

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

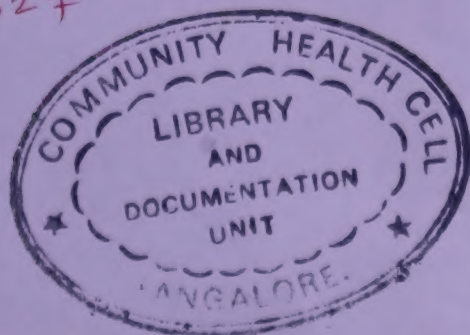
COMMUNITY HEALTH CELL

326 V Main, I Block Koramangala
Bangalore - 560 034

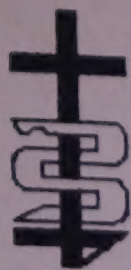
THIS BOOK MUST BE RETURNED BY
THE DATE LAST STAMPED

015-325
1496

4327



Community Health Cell
Library and Documentation Unit
BANGALORE



MISSIONSÄRZTLICHES INSTITUT WÜRZBURG

Arbeitsgruppe AIDS und
Internationale Gesundheit

Département du SIDA et
de la Santé Internationale

AIDS and International
Health Department

Departamento de SIDA y
de Salud Internacional

Missionsärztl. Inst., AG-AIDS, Salvatorstr. 22, D-97074 Würzburg

TO ALL RECIPIENTS OF LITERATURE PARCELS

Salvatorstrasse 22
D-97074 Würzburg, FRG
Tel: +49 931 80 48 50
Fax: +49 931 80 48 525

July 1996

Dear friends,

Re: Mailing List 1996/2

Herewith we send our second package of HIV/AIDS literature for 1996 which, we hope, will reach you in good order. It contains copies of 15 recent publications covering a wide field of HIV/AIDS related issues. The numbers on the list are incidental and not intended to reflect any order of importance.

We wish to draw your attention to the WHO papers:

- Preventing HIV transmission in health facilities
 - TB/HIV. A clinical manual
 - Counselling for HIV/AIDS: a key to caring
 - Provision of HIV/AIDS care in resource constrained settings,
- which offer comprehensive and concise information on issues of great importance.

The paper: HIV/AIDS and Church Development Work reflects the HIV/AIDS Policy of Misereor.

The articles:

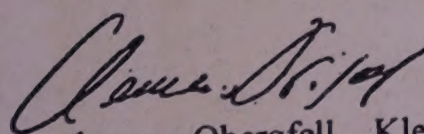
- Faithful but fearful: reducing HIV transmission in stable relationships, and
 - Stress and burnout in HIV/AIDS carers,
- touch on issues which are frequently not receiving the attention needed.

We also want to let you know that a 'Guide to Technical Support available to HIV/AIDS Projects in Developing Countries' can be obtained free of charge by NGOs in developing countries through the UK AIDS Consortium, 37/39 Great Guildford Street, London, SE1 OES, UK.

Once again, not all items included will be of interest to everyone of our addressees. We trust that you will act as multipliers by distributing copies of papers to other interested parties and by passing on those which are not relevant to your field of work.

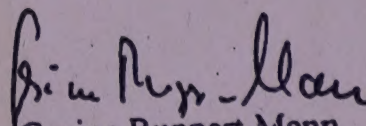
We are always grateful for your comment on the literature parcels sent to you.

With our greetings and best wishes for your work -


Clemens Obergfell

Klemens Ochel


Joachim Rüppel


Gesine Ruppert-Mann

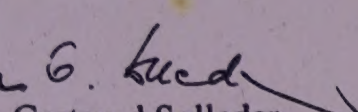

Gertraud Solleder

TABLE OF CONTENTS

1. World Health Organization: **Provision of HIV/AIDS care in resource constrained settings** (1994)
2. UNAIDS: **HIV/AIDS: figures and trends** (1996)
3. World Health Organization: **Counselling for HIV/AIDS: a key to caring. For policy-makers, planners and implementors of counselling activities** (1995)
4. Tawil, O.; Verster, A., and K.R. O'Reilly: **Enabling approaches for HIV/AIDS prevention: can we modify the environment and minimize the risk?** (1995)
5. World Health Organization: **Preventing HIV transmission in health facilities** (1995)
6. World Health Organization (WHO): **TB/HIV. A clinical manual.** (1996)
7. Zoysa, I. de, M. D. Sweat, and J.A.Denison: **Faithful but fearful: reducing HIV transmission in stable relationships** (1996)
8. Miller, D.: **Stress and burnout in HIV/AIDS carers** (1996)
9. Clarke, I.: **Are our information, education and communication-based interventions too superficial?** (1995)
10. Misereor; AIDS and International Health Department: **HIV/AIDS and Church Development Work** (1995)
11. Goldenberg, D.A.: **All children in developing countries will be affected by AIDS, not just orphans** (1996)
12. Franzkowiak, P.; Wenzel, E.: **AIDS health promotion for youth. Conceptual framework and practical implications** (1994)
13. World Health Organization: **The current global situation of the HIV/AIDS pandemic** (1996)
14. Ahrtag: **Tackling TB and HIV.** AIDS Action no.31 (1996)
15. Ahrtag: **Making progress.** AIDS Action No.32 (1996)



1

MATERIAL ON HIV/AIDS

SENT BY

**MEDICAL MISSION INSTITUTE
AIDS AND INTERNATIONAL HEALTH DEPARTMENT**

**SALVATORSTR. 22
D-97074 WÜRZBURG**

GERMANY

1

MATERIAL ON HAVARDS

RENT BY

RENTAL FROM HAVARDS

AND THE INTERNATIONAL IN ALL THE HAVARDS

RENTAL FROM HAVARDS

RENTAL FROM HAVARDS

RENTAL FROM HAVARDS

PROVISION OF HIV/AIDS CARE IN RESOURCE CONSTRAINED SETTINGS

A Discussion Paper



September 1994

*Health Care and Support Unit
Global Programme on AIDS
World Health Organization*

PROVISION OF HIV AIDS CARE IN RESOURCE CONSTRAINED SETTINGS

Page

Summary	1
HIV/AIDS and existing health care systems: capacities and utilization	1
- Equity in health care	2
- Long-term planning is needed	2
- Capacity and utilization	3
- Primary health care	3
- Community level is paramount	4
- Health care-seeking behaviour by HIV/AIDS	4
Impact of HIV/AIDS on health care systems	5
- Displacement of other conditions by HIV-related illness	6
- Bypassing peripheral health facilities	6
- Shortages of drugs	7
Needs of persons with AIDS (PWAs) and their families	7
- Needs assessment	8
Appropriate responses to the challenge of HIV/AIDS	8
- Health as a human right	9
- Comprehensive HIV/AIDS health care	9
- Concept of a continuum of care	10
- Home-based care as a community or hospital service	11
- District is the key location	12
- Seeking relief from pain and suffering	12
- Health care and prevention are inseparably linked	12
- Why prevention of other STDs?	13
- A trend towards integration of services	14
- Prevent transmission of tuberculosis	14
- Essential drugs to treat HIV/AIDS-related opportunistic infections	16
- What is the reality?	17
Requirements of health care systems relating to HIV/AIDS	17
- An efficient referral system	18
- Attitudes, training/retraining of health care workers	18
- Counselling services	19
- Discharge-referral planner	19
Conclusions	20
References	20

PROVISION OF HIV/AIDS CARE IN RESOURCE CONSTRAINED SETTINGS

Summary

This paper presents an overview of the capacities of existing health care systems to integrate HIV/AIDS care into health services, with particular emphasis on the district level, including hospital, primary health - and community-based care. It examines the impact of HIV/AIDS on health care systems, and the needs of people with AIDS (PWAs). It outlines the appropriate responses of health care systems to the challenge of HIV/AIDS, identified as comprehensive care along a continuum, and emphasizes the linking of care and prevention activities. The paper ends with a re-examination of the requirements of health care systems to adequately respond to the growing burden of HIV/AIDS.

HIV/AIDS and existing health care systems: capacities and utilization

From a public health perspective, the purpose of a health system is to protect and improve the health of total populations, including the recovery of health by treatment when prevention is unsuccessful [1].

Government health budgets cover the costs of establishing and operating the public sector health care infrastructure, furnishing medical supplies and providing human resources by training all categories of health care workers, including counsellors. Continuity in health service provision is ensured by an annual budget. Government health budgets provide, too, for the many ancillary and vital services such as a national essential drugs supply system, transport, a health information system, and public information and education for health promotion and prevention activities. Governments are also responsible for health policy formulation, allocation of resources and as a source of high-level technical advice.

NGOs have complemented government health services by increasing access to health care for rural populations through various means such as mission hospitals, outreach activities and establishing community-based health promotion and care projects. NGOs have often been able to initiate more innovative and flexible approaches to health care and sometimes NGOs and government services have successfully collaborated to provide district medical services.

Equity in health care

Many governments have national health policies which explicitly or implicitly commit them to provide equity in access to health care regardless of whether the illness is infectious, chronic or acute, curable or incurable. Diabetics must receive lifelong administration of a vital drug, insulin. Appendicitis will require surgical intervention. Liver cancer patients should receive pain relief and palliative care at the least, and those infected with HIV - a "chronic" and ultimately fatal STD - should receive treatment for their opportunistic infections, counselling and, like cancer sufferers, pain relief and palliative care.

There is inequity of access to health care in many countries of the world. In many developing countries, despite NGO and government efforts, there is substantially better access to health care in urban areas than in rural areas where the vast majority of the population lives. A few countries have made special efforts to expand access by emphasizing primary health care in rural areas but few have succeeded in sustaining this essential approach.

Quality of care has often been undermined in rural and peri-urban areas by the limited numbers of functioning health facilities, shortages of qualified health care workers and lack of essential drugs and supplies. Thus, people seeking health care will bypass poorly functioning and equipped

peripheral health facilities to seek care at fully-fledged hospitals. The net result is that hospitals are in fact delivering primary care services but at much higher costs than could be delivered by lower level health care facilities such as health centres and other district-level facilities.

In more optimistic days, many governments hoped to provide basic health care either free of charge or through obligatory insurance systems, to all their citizens. However under the pressures of the economic recession and as a result of structural adjustment policies, many government social and health services have been cut or severely curtailed. Nowadays, most governments have been forced to seek ways of sharing the burden of costs of providing health care; the means of accomplishing this are still being sought or are under investigation but cost sharing or cost recovery for medicaments is one of the most widely used.

Long-term planning is needed

Long-term planning to meet the demands for health care is rarely undertaken. This is partly due to the poor quality of health information systems and the consequent lack of reliable morbidity data for planning purposes. The morbidity data which does exist is often collected directly from health care facilities by an essential drugs management programme which uses such information to plan drug procurement and prepare guidelines on rational use of drugs. There may be very little coordination and information-sharing between various sections of a health ministry such as the planning office, health information services, the essential drugs programme, the national AIDS and national TB programmes, and others.

Unexpected or unplanned-for epidemics have usually meant acute, temporary shortages of supplies and services in a health care system. However, the HIV/AIDS pandemic is henceforth neither unexpected nor short-term. Long-term planning for health care, based on projections of the future progression of the pandemic, is now an urgent priority.

Capacity and utilization

The capacity of the health care infrastructure to respond to demands for health care depends on the availability and distribution of human resources and health facilities. Public resources have been concentrated in tertiary infrastructure and equipment at the expense of investment in lower level facilities, especially health centres. High population growth rates make it difficult for health centres which can effectively serve around 5000 people, to maintain, let alone expand, coverage. Most countries need to considerably increase the numbers of health facilities - in the case of some countries, dramatic increases are needed - in order to achieve 60% health care coverage by the year 2000.

The imbalance in access to health care between rural and urban areas are exacerbated by poor siting of health facilities. Furthermore, according to a World Bank assessment, existing health facilities in a number of countries in Africa have undergone serious deterioration in the past decade; some have declined beyond the point of repair [2].

In many resource-constrained settings trained human resources are poorly distributed. There may be under- or inappropriate utilization of trained staff resulting in substantial attrition by moves from the public sector to the private sector or - more seriously - by emigration. There is also under-supply of trained personnel which is partly due to the very low salary scales in the public sector. The population-to-trained staff ratio is often unacceptably high leading to both inequity and poor quality of the health care delivered.

In recent times, in resource-constrained settings, all levels of health care systems have been under constant strain from demand for care by the case-load of common morbidities. Financial and human resources are thinly spread in the lower tiers of health care systems and it is a rare health centre which has sufficient essential drugs and supplies of needles, syringes and other medical supplies to meet its needs. Since the onset of the HIV/AIDS epidemics and the worsening of the tuberculosis epidemic in these countries the burden of demand on their health systems has been relentlessly aggravated.

Primary health care

Primary health care is intended to be the interface of contact between communities and the formal health system, bringing health care as close as possible to where people live and work. *It constitutes the first element of a continuous health care process.*

Primary health care broadens the concept of the health system to include not only health facilities but communities and families as agents of health. The encouragement of healthier life-styles and, the promotion of oral rehydration solutions with which mothers could treat childhood diarrhoea are examples of family-based initiatives.

Community level is paramount

The community level was intended to be the centre and the focus of primary health care backed up by personnel and facilities at the first referral (intermediate or district) level which was perceived as the main direct support and the link between local health activities and the successive levels of referral and specialized services. The community was to participate on a voluntary basis and there was to be a real devolution of responsibility and power, including the control of financial resources, towards the periphery.

In some countries policy-makers remained unconvinced about shifting resources away from central hospitals towards primary health care. However, world-wide, the concept and practice of district level health care has been initiated in over a hundred countries and in thousands of districts. District Health Teams are responsible for day-to-day management and District Management Committees try to foster intersectoral collaboration in the health, education, water and sanitation sectors.

Community health worker (CHW) or village health worker (VHW) programmes aimed to extend modern health care beyond hospitals and health centres and to act as a catalyst for community development.

According to a World Bank analysis of various studies, the performance of CHW or VHW programmes in Africa has been mixed and sometimes poor. CHW programmes have worked quite well when their role as liaison between community and health care system is clear and where they receive support from the system. It is reported, however, that the contribution of CHWs to efficient, equitable and sustainable health care in Africa has been blunted by lack of constant support and supervision [2].

In respect to HIV/AIDS, what should be the role of community health workers? As part of health promotion activities should they be expected, for example, to initiate with individual community members the question of voluntary testing for HIV? Can they successfully refer suspected TB cases - with or without HIV co-infection - for diagnosis and treatment?

Home-based care for very ill members is a rather different component of primary health care at the family level but it is rooted in traditional caring practices of many cultures. With respect to HIV/AIDS it implies bringing moral support, health promotion such as the use of condoms for safer sex, and clinical and nursing support for people with HIV/AIDS or other chronically ill people, into the family setting. Should it also imply responsibility on the part of the care giver for dispensing medications for treatment, and for palliation including possibly pain relief?

In addition, full use of the community level for the support of home-based care needs to be made. But are the mechanisms for community involvement in health care too poorly developed and the cords linking the community to the next level of referral too tenuous to bear the weight of demands on them?

The HIV/AIDS pandemic is swelling the demands on all levels of health care at a time when they are particularly financially vulnerable and when much of the development work remains to be done in that crucial level of primary health care: involvement of the community. There are some world-class examples of community voluntary participation in the health and welfare of the community, (see page 10) but as yet these programmes reach only a fraction of those in need.

Health care-seeking behaviour by people with HIV-related illness

The first point of contact for those in need of care for opportunistic infections will be health centres for diagnosis, treatment, relief of suffering and possibly counselling if they are identified as HIV-positive. Health centres are likely to be providing symptomatic treatment to many HIV-positive people without necessarily being aware of their sero-positive status. A study in 1992 among health centres in rural Monze district in Zambia, found that 18% of adult attenders were HIV-positive [3]. This level of seroprevalence came as a surprise to staff who were unaware that there were HIV-positive people among the health care seekers in their facilities.

People with HIV/AIDS are quite likely to seek help at hospitals. In many high prevalence countries the increasing numbers of HIV-infected patients make heavy demands on limited clinical resources - 40% -80% of medical beds may be occupied by patients with HIV/AIDS-related conditions. A survey carried out in 1992 in a major hospital in Kampala, Uganda, showed 55% of patients admitted to medical wards were HIV-positive [4]. In a major teaching hospital in Lusaka, Zambia, the figure was 70% (3).

If health care systems cannot be made to function effectively at all levels, will the burden of HIV/AIDS become unbearable?

Impact of HIV/AIDS on health care systems

Critical information which would allow a thorough assessment of the impact of HIV/AIDS on health care systems, is often lacking. For example, it is not known how many HIV-infected people will seek health care in the available health care infrastructure, how many opportunistic infections they will contract during the illness, whether they will seek treatment for each of these and at which health care facility.

Important information which is available however, concerns financial resources available for health care. Most resource-constrained countries spend US\$5.00 or less per capita on health care but the costs of treating an AIDS patient have been calculated to be at least twice GNP per capita. The actual cost will depend on where the health care is delivered and whether or not the recommended treatment can actually be provided. Essential drugs, for example, are often in short supply and

may not be available when health care is sought, especially at intermediate level health facilities. Treatment for tuberculosis, alone, which is the most important opportunistic infection will cost many times the usual expenditure per capita on health care.

Estimates of the total economic costs must include not only public expenditures but also private expenditures associated with health care for HIV/AIDS including medical care, drugs, diagnostics, transportation and other expenses such as special foods. Funeral expenses should be included in private expenditures; in some cultures these expenses can be devastating to the family finances.

It has proven nearly impossible to calculate total costs of HIV/AIDS care with any degree of certitude because of the unknown parameters - how many seek care; where; how often; what resources are actually expended, etc. However, estimates of lifetime treatment costs ranging from several hundred to several thousand US dollars indicate immense potential expenditure on health care associated with HIV/AIDS.

WHO/GPA reckoned, in 1992, that the total cost of HIV/AIDS treatment in developing countries amounted to US\$ 337 million and costs for people needing care in those countries amounted to US\$ 418 million. By the year 2000 these costs were estimated to have risen to US\$ 1.1 billion and US\$ 1.4 billion in the developing countries. These figures give an indication of the potential "savings" to be made by effective prevention programmes for HIV/AIDS. It is more than likely that the total cost in billions will far exceed the figures that have been projected.

To speak of "impact of HIV/AIDS" is like throwing a stone into a pool: the ripples keep expanding outward until the surface of the entire pool is moving. It is nearly impossible to locate where the impact of HIV/AIDS on one sector - the family, agriculture, industry, etc - ends and where it begins in another sector. We are concerned here only with assessing - in so far as this is feasible - the direct impact on health care systems in terms of the costs of care as described above.

It has been reported that in hospitals in southern Zambia the HIV epidemic is having a major impact on health service staff, particularly nurses [5]. The hospital workload has greatly expanded whilst the shortage of nursing staff grows. Whether due to "burn-out", fear, or increased morbidity and mortality, nurses are being lost at an unsustainable rate. There appear to be quite high rates of HIV infection among female nurses in Zambia. In two hospitals in Southern Province, where high seroprevalence in the general population is reported, mortality among nurses has increased from 2 per 1000 nurse-years in 1980-85 to 26.7 per 1000 nurse-years in 1989-91. Absenteeism among nurses has also increased which leaves the remaining nursing staff with an even heavier workload.

Displacement of other conditions by HIV/AIDS-related illness

The case-load of hospitalized HIV/AIDS-related conditions may be displacing the usual mix of morbidities seen by hospitals and making it nearly impossible to manage the latter patients and maintain other services at the same time.

A study which randomly sampled more than 200 admissions in 1988 to Mama Yemo Hospital in Kinshasa revealed that about half were sero-positive [6]. Since the hospital was fully utilized before the epidemic, the inevitable conclusion was that substantial numbers of other conditions were not being treated. In addition, the high mortality rate among non-AIDS patients indicated that it was mostly the very ill patients who were gaining admission to the hospital.

A recent study compared HIV infection in acute medical admissions to Kenyatta Hospital, Nairobi, in 1988-89 and again in 1992. The study concluded that HIV seroprevalence in medical patients

has doubled in 3 years and that the epidemic is adversely affecting the health care available to seronegative patients. With the increased workload due to HIV/AIDS, 20% fewer seronegative patients were admitted and mortality among them increased from 15% to 23% [7].

Quantitative data showing that other morbidities are being crowded out of hospital care are only now becoming available. When 80% of medical beds in a major city are occupied by HIV-related illness, it is logical to assume that patients with other kinds of morbidities will not find a place unless they have a life-threatening illness requiring hospitalization and intensive supportive care.

If displacement by HIV/AIDS is proven beyond doubt, what is the solution? Should additional hospital wards be built, furnished and staffed? It is not unusual these days that 70%-90% of patients on some TB wards are reported to be co-infected with HIV. Often these patients are too sick for ambulatory care. What then? Are more TB wards also needed?

These questions are more than hypothetical; health care systems, especially in Africa, are already facing such institutional dilemmas.

Bypassing peripheral level health facilities

In many countries, it is the hospital level, and particularly the tertiary facilities, which are bearing the brunt of the burden of the HIV/AIDS epidemic as health care seekers who suspect they may be HIV-positive bypass local health care facilities and go directly to higher health care levels. Furthermore, staff of peripheral health facilities are often not "AIDS aware" nor have they received training in diagnosis and clinical management of HIV/AIDS.

Other reasons for bypassing facilities include: frequent drug shortages in peripheral facilities (although health care seekers at hospital level will often be given a prescription to buy drugs outside the hospital); the perception that there is more staff expertise in hospitals; and preference for the anonymity of a larger health facility.

Many of the symptoms of HIV-related illness can be managed adequately, and relief and comfort easily provided, with inexpensive essential drugs which figure, for the most part, on national essential drugs lists. However, the HIV epidemic involves significant additional morbidity; even if only a proportion of HIV-infected people seek health care, this represents a substantial increase in demand on medical supplies in general and drug supplies in particular.

Shortages of drugs

Allocations for essential drug supplies in national budgets are already insufficient and drug shortages in the health care system will become increasingly frequent with a concomitant loss of confidence in the ability of health care systems to deliver adequate care.

Particularly serious are shortages of drugs used in the chemotherapy of tuberculosis. Among the vastly increasing numbers of TB patients, some will be forced to interrupt treatment due to drug shortages. Patient compliance with drug treatment over many months has always been a difficulty in TB control programmes, but this may now be compounded by problems of supply due to budgetary constraints.

Needs of people with AIDS (PWAs) and their families

Health care should be based on the needs of PWAs as identified by them. These needs vary substantially according to socio-economic context and culture. It has become clear that basic human rights of PWAs have been violated in many countries. Rejection and discrimination have been widely reported and are clearly prejudicial to the chances of receiving adequate care and attention.

PWAs have expressed their needs and demands in various fora, but for obvious reasons, PWAs from developed countries have been able to make known their needs more widely and forcefully than PWAs in developing countries.

In more affluent settings, where for the most part, basic needs for food, shelter and treatment for opportunistic infections are assured, PWAs demands include the following: the right to protection in employment; to confidentiality; to medical care and access to treatment, including new drugs; to bereavement counselling; to emotional support; and to consideration of their sexual needs.

The demands of PWAs in resource-constrained settings relate to basic needs such as drugs to treat opportunistic infections, financial help to pay for food, support so that they and their surviving children may stay in the family home, and some assurance that their children will be cared for after their death.

Needs assessment

Very few studies have been undertaken in Africa to assess the needs of PWAs and their partner and families. Assessment is complicated by the fact that their needs change as the disease progresses, and that needs in a clinical setting are different to those in a home setting. It is difficult to devise representative samples for quantitative studies due to patient identification and confidentiality. Qualitative studies, however, have given some insight and understanding into the variety of needs.

A study in rural Malawi, in 1990, undertaken in preparation for the development of a community and home-based care programme, used in-depth interviews and focus group discussions among PWAs and care givers. The needs expressed fell into four main areas:

i) food; repeated illnesses in productive adult members of a household, whether it be a woman or a man (or both), results in a progressive fall in income and in the last stages of the disease, in no income at all. In families where food is grown rather than bought, food production falls gradually and when the PWA is unable to work, no food may be available for the family. In areas of widespread poverty, the additional disease burden is devastating on the family circumstances;

ii) clothing; skin lesions and repeated, prolonged episodes of diarrhoea make frequent changes of clothing a necessity, from the point of view of both hygiene and comfort.

iii) medicines; treatment for common ailments and opportunistic infections is needed. Peripheral health centres in poor countries frequently lack supplies of essential drugs for these indications; this contrasts sharply with demands expressed by PWAs in affluent countries for access to innovative treatment trials;

iv) support for surviving children; continued schooling is of great concern, particularly provision of school fees and uniforms, since schooling is seen as the only hope for a brighter future [8].

Surprisingly little concern was expressed about safeguarding confidentiality or combating discrimination. When patients are being cared for at home, in their community, usually in the late stage of HIV disease, the family and the community have long ago learned of and accepted the patient's HIV status.

In Zimbabwe, a qualitative study among 41 families with a seriously ill or deceased parent was carried out to provide insight into needs and coping mechanisms. The needs most commonly reported related to the alleviation of emotional stress and the additional economic hardships. These needs were often the result of paternal desertion, neglect or conflict over wives and children, inheritance of property, or lack of acceptance by the extended family [9].

In Uganda, a TASO evaluation of its activities yielded similar information on needs of PWAs; medical treatment, counselling and material assistance were the needs most often expressed. A relatively high proportion of PWAs (76% of 703) felt their disease status was accepted by the community and 79% felt it was accepted by families.(10)

Stress was most acute: at the time of diagnosis; when regular or occasional cash income was lost; when need arose for specific additional expenditure(e.g. frequent transport to hospital, funeral); when inheritance issues arose; when the wife or mother became ill and died; and, when the extended family capacity, or willingness, to assist broke down.

The studies in Malawi and Zimbabwe demonstrate that, at the community level, AIDS might just be seen as "another fatal disease among us" but that does not mean that communities are prepared, materially or emotionally, to deal with its devastating consequences.

Community views may be very mixed concerning acceptance of the disease. In a seriously affected area in Zambia women were asked about who should provide care if a relative had AIDS. Around 62% thought family or friends should be care givers; 23% thought it was the task of government services; and nearly 5% thought that PWAs should not be cared for at all; this response was higher in rural areas (6%) than in urban areas (3%). Somewhat surprisingly, very few respondents mentioned religious institutions (3).

Appropriate responses to the challenge of HIV/AIDS

Health as a human right

As in all matters relating to public well-being, political will is paramount. Nearly all governments are signatories to the International Covenant on Economic, Social and Cultural Rights. Article 12 of the Covenant states that Parties to it recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Further, Article 12 states that steps to be taken by signatories to achieve full realization of this right shall include, *inter alia*, (c) *The prevention, treatment and control of epidemic, endemic, occupational and other diseases;* and, (d) *The creation of conditions which would assure to all, medical service and medical attention in the event of sickness.*

Comprehensive HIV/AIDS health care

HIV-related illnesses are opportunistic infections caused by native environmental organisms and are thus illnesses which could be incurred by other members of the population. However, in immunosuppressed individuals infected with HIV, the illnesses are more frequent, severe and prolonged but, in general, they are treated with the same range of medications typically used in basic health care. These medications - quite limited in number - are most often included on a national list of essential drugs.

In HIV/AIDS, conditions occur, not infrequently, which would be very rare morbidities in the general population, such as cryptococcal meningitis, aggressive Kaposi's sarcoma in young persons, and oesophageal candidiasis for which medicaments are not readily available - or not available at all - in the drug supply system serving public sector health facilities. The full range of pathogens associated with HIV infection in developing countries (possibly differing by region), is not known in its entirety [11].

Health care as it concerns HIV/AIDS has unquestionably introduced an additional component - that of counselling - and has strengthened another, that of the role of the community.

Comprehensive health care in HIV/AIDS comprises four main components: i) clinical management; ii) nursing; iii) counselling; and iv) social support. These four components must function in a coordinated way in a *continuum of care*.

The Health Care and Support (HCS) unit of the WHO Global Programme on AIDS describes the four components of comprehensive HIV/AIDS care as follows [12]:

- i) Clinical management includes appropriate diagnosis, rational treatment and planning for follow-up [13,14];
- ii) Nursing care includes the provision of medical care, maintenance and promotion of hygiene and nutrition, infection control practices, provision of palliative care, counselling and education of family members on prevention and to provide care for the afflicted family member [15];
- iii) Counselling, the provision of psychosocial support, includes helping individuals make informed decisions on HIV testing, stress and anxiety reduction, planning for the future, promoting positive living, networking, and promoting behavioural changes. HIV antibody testing, in association with pre-test and post-test counselling can play an important role in HIV/AIDS prevention;
- iv) Social support includes provision of information, referral to support groups, welfare services and legal advice; it provides help in planning care and schooling of surviving family members and, where feasible, material assistance can also be provided.

Concept of a continuum of care

Comprehensive HIV/AIDS care should be accessible at several points along a continuum extending from home to community to different levels of health care facilities. Entry into a continuum of care can be at one of several points: a voluntary counselling and testing centre, a health care facility or a community support group. It is important that, whatever the entry-point, the four components of health care - clinical management, nursing, counselling and social support are provided.

This approach requires coordination between points on the continuum; for example, between district-level health facilities and community-based services - most often provided by nongovernmental organizations (NGOs), private voluntary or religious groups - as well as a highly developed awareness of how, where and when appropriate health care can best be delivered.

An efficient and effective referral mechanism is essential for a continuum of health care for HIV/AIDS patients. Referrals may be to and from hospital or clinic to community-based services, as needed. Outpatient and home-based care and community-based services should form the backbone of HIV/AIDS health care with support from the mid-level (district) health facility. Community-based services may comprise day care centres, support groups, organization of income-generating activities and various other services provided by NGOs and voluntary groups. An area in which community-based services can make a significant contribution is in the provision of support for families affected by AIDS.

Closely linked to community-based services and, in fact, an integral part of them is home-based care which will include training of family members as care providers; the management of common symptoms; provision of supervision and guidance by community-based workers, palliative care and moral support, support for families to maintain hygiene and nutrition, and linkages to social welfare systems [16].

The community is the ideal place to meet the many needs of those affected and it is becoming clear that a strictly hospital-based service for the care of HIV-infected people is untenable, inappropriate, and wasteful of local resources [17]. Community-based care will only function effectively in conditions of tolerance, support and solidarity. Denial, fear, discrimination and stigma need to be dispelled through a continuous dialogue to raise awareness about AIDS, including education for prevention.

Home-based care as a community service or a hospital service

A home-based care programme aims to provide medical care to HIV/AIDS patients. Care should include: essential drugs; nursing care, including infection control practices; counselling on prevention and problem-solving; education to impart to the care-givers a deeper understanding of the illness; provision of health care aids and possibly of condoms and, depending on circumstances, pastoral counselling for spiritual needs [18].

There are several models of home-based care; some are hospital-initiated (often by mission hospitals) for example, Nsambya Hospital, a private Catholic hospital, in Uganda; Kitovu Hospital Mobile AIDS Home Care in Rakai and Masaka Districts in Uganda; The Salvation Army Chikankata Hospital in Zambia; and the Monze District Hospital Community and Home-Based AIDS Care, Monze District, Zambia; and the University Teaching Hospital Home-based Care programme, Lusaka, Zambia and many others [19]. These projects depend on having vehicles for transport of outreach teams which often includes a clinician, a nurse and/or a counsellor to visit patients in their homes who were diagnosed as having AIDS, have had hospital discharges and planned follow-up. These account for only a fraction of HIV-positive people in the population who need now, or will soon need, comprehensive HIV/AIDS care. Gradually, a number of these programmes have expanded to involve community-based volunteers and health workers and rely more on existing community-based structures in order to increase coverage and sustainability.

Other home-based care models started as community-based family support groups and then expanded to link up with regular health services. One of these, which has been longest-organized,

is the AIDS Support Organization (TASO) in Uganda. TASO is a voluntary organization many of whose members are themselves affected by or infected with HIV [10].

These home care programmes make great efforts to reduce discrimination, stigma and fear and to stimulate participation of the community in the care of AIDS patients. Hospital-initiated and community-based home care programmes exist now in many other countries such as Kenya, Nigeria, Thailand, South Africa, Uganda, Zambia and Zimbabwe. These programmes are organizing care and prevention activities at the community level, providing an entry point on the continuum and grasping an opportunity to sensitize members of the community about HIV/AIDS.

In addition to the clinical supportive care given to the patient, volunteers from the community assist with chores in the home, care for people without relatives, bring the community nurse to the sick person, arrange burials, collect money to buy food, and provide spiritual support when it is sought.

In the community, especially, it is recognized that care of AIDS patients is only one facet of the problem. *Poverty is the main constraining factor.* Lack of food, rejection and isolation, intense worry about the family left without means of support and the fate of orphaned children colours the emotional climate of an AIDS-afflicted household. Unfortunately, negative attitudes and a tone of rejection towards those afflicted with HIV/AIDS may be encountered at first from health care staff.

A strong referral system is a prerequisite for community-based home care programmes. Community health workers must be able to refer home-based patients to a health care facility when their illness status requires it and, conversely, hospital-based health workers, such as clinicians, should refer HIV/AIDS patients to peripheral health facilities and NGOs working in the community with local resources. The problems associated with referral can be overwhelming in isolated areas and where there is no money for transport of the patient.

Material support in the form of food or school fees is the help that is most sought by HIV/AIDS afflicted families. This raises questions about what home care can most usefully provide. Should it be restricted to health matters, with social support being provided by other community-based organizations? How can the various elements of home care best be implemented and at which level of the health care system? And the biggest challenge - how to provide home care for all those in need?

District is the key location

Public sector health care facilities also include mission hospitals and clinics which may provide up to half of all health care in some developing countries. While they are generally supported by donor funds, some of them also receive a certain level of support from the government health budget as, for example, bed grants and a proportion of their essential drug supplies.

Patients should be referred to a mid-level health care facility, preferably a district-level hospital or clinic, nearest their home if short-term inpatient services are needed. Referral by mid-level services to tertiary care level - a hospital with specialist services - should only take place for certain required laboratory procedures or specialized diagnostic and treatment services (for example, cryptococcal meningitis, cytomegalovirus retinitis, and cancers). Terminal care for end-stage AIDS patients can be managed most humanely at home provided the care-giver can responsibly give medications, including for pain relief (codeine and morphine) and palliative care, and provided that the care-givers themselves receive social support.

The district is perceived as the appropriate level for sustainable health development within the context of primary health care and as the functional link between community-based services and public sector health care [20].

Seeking relief from pain and suffering in the health care system

Justifiably or not, the credibility of the health care system is strongly affected by attitudes of health facility staff and by the availability of drugs. While drugs alone are not sufficient to provide adequate health care, confidence in the system is definitely enhanced when there is a regular supply of essential drugs in health facilities to treat the most common conditions [21].

One of the reasons health care seekers bypass health centres and even district hospitals for the larger, urban-based hospitals is that medicines are more likely to be available there. It is clearly a waste of time for them (and of precious money for transport) to go to a health facility where no medicines can be provided. There may be a broad range of drugs available for sale in primarily urban-based pharmacies but these are usually far too expensive for the majority of those in need of them.

Scarcity of financial resources make it practically impossible for governments in developing countries to procure the quantities of essential drugs required to treat the expected burden of morbidities seeking treatment. With the rapidly increasing numbers of HIV/AIDS patients seeking treatment for opportunistic infections, the impact on drug supplies in public sector health care can only be exacerbated [22,23].

Health care and prevention are inseparably linked

Prevention is indisputably the most important objective of any national AIDS programme and a responsibility taken on by various ministries, NGOs and the private sector. Within health systems, prevention consists of: the promotion of safer sexual practices, prevention of transmission through blood and the control and prevention of curable STD.

For the promotion of safer sexual practices, a variety of approaches are possible in the context of providing care. Person-to-person communication at the bedside with patients (with opportunistic infections or AIDS) and their families; small group discussion in outpatient waiting rooms, integration of HIV/STD health education at MCH clinics, active promotion of the use and provision of condoms through various outlets in the health system are just a few examples.

Prevention messages may suddenly have a lot more force when individuals and communities are directly and personally confronted with AIDS and when tragically, sero-prevalence in the population has already reached high levels.

At every point along the continuum extending from home to community to the different levels of health care facilities, with their general and specialized services, opportunities for prevention of HIV/AIDS, other STDs and tuberculosis, should be exploited.

Why prevention of other STDs ?

Every year there occurs worldwide an estimated 250 million or more new sexually transmitted infections [24]. They are responsible, directly or indirectly, for an enormous burden of pain, discomfort and serious morbidities including sterility, stillbirth, miscarriages, blindness, brain damage and cancer. They rank second in importance among diseases, worldwide, in women aged-

15-44 years. Four curable STDs - gonorrhoea, chlamydial infection, syphilis and chancroid - rank among the top causes of healthy days of life lost in sub-Saharan Africa [25].

It is widely recognised but bears repeating: STDs, especially those causing ulcerative lesions such as chancroid, syphilis or herpesvirus infection, facilitate the transmission of HIV. STDs probably also enhance both HIV infectivity and susceptibility among men and women [26].

STDs are still "private" diseases and subject to stigma and embarrassment. Among males, the tendency is to late presentation for diagnosis and treatment; among women, who are often unsymptomatic or have "only" vaginal discharge, the best opportunity for diagnosis and treatment may be attendance at antenatal and/or maternal and child health/family planning (MCH/FP) clinics. However, many women have neither the financial means nor the time to seek treatment even when they are aware that they have an infection.

Among other reasons cited for delay in seeking treatment for STDs are: poor quality of the health care facilities which are often understaffed; personnel who lack an understanding approach to patients with STDs; and lack of supplies of essential and other drugs.

A trend towards integration of services

The trend is definitely towards integrating HIV/AIDS and STD programmes; any degree of coordination of HIV/AIDS and STD programmes should be promulgated and nurtured. Any consultation for a possible STD - whether within a public sector health facility or a community-based service - should be seized as perhaps a unique opportunity for education on safer sex and use of condoms for prevention of STD and HIV infections, and referral to counselling if needed,

STD prevention and health care must aim to i) interrupt the transmission of sexually acquired infections; ii) prevent development of diseases, complications and sequelae; and, iii) reduce the risk of transmission of HIV. These objectives can best be achieved through primary and secondary prevention carried out at the site of contact between a health care seeker and a health care provider. Preferably, these prevention and care interventions should be carried out through an integrated approach at the district level [27].

As there is a lack of simple, inexpensive diagnostic tests WHO recommends a syndromic diagnosis approach for case management of symptomatic STDs in resource-constrained settings. The same treatment regimens should be followed at each level of the health care infrastructure. Efficient case management also includes: education on risk reduction and prevention; promotion and provision of condoms; partner notification and treatment; and clinical follow-up where appropriate.

Because of problems of resistance or ineffectiveness, the treatment modalities for curable STDs now often specify third generation cephalosporins or fluoroquinolones which far exceed the costs of the earlier-used antibiotics. Herpesvirus infections are incurable; treatment with antivirals such as acyclovir is marginally effective and very expensive. Diagnosis of some STDs is very difficult in women and, in fact, they do not readily present for treatment; the conditions are frequently non-symptomatic until complications arise. The development of simple and rapid diagnostic tests, especially for gonorrhoea and chlamydial infections in women, is a hopeful area. The basic technology exists (enzyme immunoassays) but it is difficult to predict when it might come into widescale use.

The difficulties and constraints of organizing and managing an effective integrated programme for the control and prevention of STDs and prevention of HIV should be repeatedly underscored.

Do existing integrated STD prevention and control programmes incorporate measures for prevention of HIV infection? Does case management within STD control programmes foster a role for some of them to serve as a pathway for entry into a continuum of care for HIV/AIDS?

Prevent transmission of tuberculosis

The two pandemics of HIV/AIDS and tuberculosis do not only exist side by side but are co-mingled. Untreated tuberculosis is also often a fatal disease. Large proportions of populations in developing countries harbour a latent focus of TB, only held in check by intact immune systems; this accounts for it having become the most prevalent of the opportunistic infections among HIV sero-positives. In Africa, dual infection is present in nearly half of the adults known to be infected with HIV. Tuberculosis can occur early or in later stages of HIV infection and there is a cumulative lifetime risk of 30% of developing active disease. Among newly diagnosed patients on hospital TB wards, an HIV prevalence of 50-70% has been demonstrated.

Historically, national TB control programmes have been vertically planned and managed, undoubtedly with good reason. The chemotherapy of TB is long, onerous and beset with compliance problems; this promotes treatment failures, the occurrence of drug resistant organisms and opportunities for propagation of the infection to the non-infected. Given the relative ease of aerosol/droplet infection to close contacts, especially to children under five and HIV-positive people, it is of enormous public health importance to render TB cases non-infectious as rapidly and effectively as possible and to maintain that status.

As a widespread chronic disease which is completely curable with adherence to efficacious multi-drug treatment regimens, tuberculosis may be considered a special case as concerns drug supply. Drugs should be supplied within the framework of an effective national tuberculosis control programme where both the supply of drugs to patients and the consumption of drugs is strictly controlled. Drug resistance is fostered in settings where drugs are supplied without rigorous control procedures.

The concept of isoniazid prophylaxis is an attractive one for HIV-positive people who are tuberculin positive and sputum negative, i.e. who do not have active tuberculosis. However, caution must be exercised as there are many opportunities for isoniazid drug resistance to develop as, for example, among HIV sero-positives who do in fact have active TB but it is not recognised. A recent feasibility study has outlined the many pitfalls in attempting to organize isoniazid prophylaxis [28]. There are vast problems with screening efforts which can permit decisions to be taken about who should receive isoniazid. It is doubtful if prophylaxis should be contemplated in settings where efficient and effective screening cannot be carried out.

Under the favourable circumstances of an efficient tuberculosis control programme and a continuum of HIV/AIDS care that extends into the community, it should be feasible to train CHWs to oversee proper compliance with tuberculosis drug therapy regimens and, in the best of circumstances, possibly even of isoniazid prophylaxis although this subject still requires further study and operational research. It will be very useful if tuberculosis control programmes become increasingly "HIV/AIDS aware". Clinicians in particular should be able to recognize and treat TB patients with HIV-related disease. TB treatment programmes in hospitals, clinics or on an outpatient basis could be a suitable entry-point for co-infected patients into a continuum of HIV/AIDS care.

Essential drugs to treat HIV/AIDS-related opportunistic infections

The most important opportunistic infection in HIV/AIDS is most certainly tuberculosis. In association with the HIV/AIDS pandemic, tuberculosis is resurgent and also pandemic. About half the HIV-infected people with tuberculosis have no clinical features suggestive of HIV infection.

People dually-infected with HIV and TB respond well to TB chemotherapy. Compliance with treatment regimens can be very burdensome if they are long and expensive but the change to short-course regimens should improve compliance and help to limit emergence of resistant strains. Thiacetazone needs to be removed from treatment regimens because of a high incidence of toxicity among HIV-infected individuals [29]. Unfortunately, substituting the inexpensive thiacetazone with the cheapest alternative, ethambutol, considerably increases the cost of treatment. Even at costs estimated to be as little as US\$ 13.00 for a curative course of TB chemotherapy [30], this amount far exceeds the expenditure, per capita, on all drugs in public sector health care which may be as little as US\$ 2.00 in some developing countries.

TB control programmes in developing countries have received aid from agencies such as the International Union Against Tuberculosis and Lung Diseases. In order to assure continuous, uninterrupted supplies of anti-TB drugs in the face of the expanding TB pandemic, developing countries will certainly need outside help for bulk purchasing of drugs, amongst other things.

Despite the fact that a HIV-infected person is likely to be a young, economically productive member of the community who will undergo prolonged disability, severe pain and early death, it is unlikely that in developing countries, attempts will be made to treat the virus infection itself - antiretroviral compounds are exorbitantly expensive and are not curative. In contrast, there is clear public health benefit in treating tuberculosis in HIV-infected persons; it not only reduces illness but also helps prevent spread of the contagion.

For other opportunistic infections caused by local environmental pathogens, *The guidelines for the clinical management of HIV infection in adults and in children* [13,14] developed by WHO, are models for countries to adapt to their own situation. The medicaments selected for health care at mid-level (district) facilities recommend drugs from the WHO Model List of Essential Drugs [31]. The choice between drugs is made on the basis of a careful evaluation of relative efficacy, safety, quality, price and availability. Price is a key criterion for most countries and in cost comparisons between drugs, the cost of total treatment and not just the unit cost of the drug must be taken into consideration.

GPA/HCS has described a set of commonly-used drugs in the treatment of HIV/AIDS-related conditions [32]. Ideally these drugs should be identified in national treatment guidelines and in the context of the national essential drugs programme. There is no strict division between drugs for HIV-infected persons and those who are seronegative; as in selecting drugs for a national essential drugs list, the main criterion is affordability. Hard decisions will have to be made about whether to procure drugs for treating cases of HIV-related toxoplasmosis, cryptococcal meningitis, systemic fungal infections or aggressive Kaposi's sarcoma.

In an assessment of all drugs mentioned in the guidelines for clinical management of HIV infection in adults, a GPA internal Working Group proposed the drugs in the following table as useful in the care of HIV/AIDS. All the drugs are from the WHO model list of essential drugs, e.g. those drugs most needed for the health care of the population:

Commonly Used Drugs for HIV/AIDS [32]

Indication	Drug
Dehydration	oral rehydration salts (ORS)
Bacterial infections	co-trimoxazole penicillin (oral) ampicillin
Fungal infections	gentian violet nystatin (oral and ointment) ketoconazole*
Parasitic infections	metronidazole
Pruritus	calamine lotion
Tuberculosis	isoniazid rifampicin pyrazinamide ethambutol

*ketoconazole is expensive; limited supplies may be considered with enforceable criteria for its use.

A serious problem in estimating and procuring essential drug supplies (alluded to earlier) relates to the availability of quantitative information on the different types of morbidities in the population. The WHO Action Programme on Essential Drugs (DAP) has formulated two methodologies, one based on numbers of morbidities and standard treatment regimens and one based on past consumption of drugs, for estimating drug requirements and has tested them extensively in essential drug supply programmes in developing countries [33]. GPA has developed a computer software programme to adapt the DAP methodology for estimating drug requirements for HIV/AIDS [34].

What is the reality?

In general, people with HIV/AIDS can enter the public sector health care system like other health care seekers, and they will face the same shortages or even absence of essential drugs. They will perhaps receive treatment for an opportunistic infection and leave the system without ever being explicitly identified as HIV-positive. Health care systems cannot at present offer routine, spontaneous and widespread HIV testing, or pre- and post-test counselling, to those entering inpatient/outpatient care.

How then to identify HIV-infected people who should be eligible for entering a continuum of care with its elements of counselling and its subsequent clinical management and nursing care and its social support, including eventual home-based care? Other than via a voluntary testing centre, a hospital discharge with planned follow-up or, possibly, via a specialized outpatient service or STD clinic, how does a person enter the continuum for HIV/AIDS health care? Can people enter the

continuum in the absence of an HIV-positive test or is this an absolute prerequisite for entering the continuum of care?

How can health care along a continuum best be delivered? Can it be effectively organized within the available public sector health care infrastructure which ranges from health centres to district level health facilities - clinic or hospital - to tertiary level facilities such as referral and teaching hospitals, located only in urban areas?

Or is the answer mainly in the hands of NGOs and private or voluntary groups who work primarily at the grass-roots level organizing community support and what might be seen as a parallel health care system for HIV/AIDS whose core is home-based care with intermittent support from public sector health care facilities?

As concerns HIV/AIDS care and in seeming contradiction to primary health care concepts, the public sector health care infrastructure does not actively seek clients for its services except through the functions of its health promotion and prevention activities. On the other hand, organizations in the community - NGOs and the private and voluntary organizations - have access to those people in the community and in marginalized groups who need to enter a continuum of care for HIV/AIDS.

Could a bridging mechanism be devised between the public sector health care infrastructure and the NGO/private and voluntary groups that will permit a more substantial number of those in need of it to enter the continuum of care?

Requirements of health care systems relating to HIV/AIDS

The function of health care systems is to provide care to all those members of populations who seek it, for any health condition. The care provided must be of an adequate quality to sustain confidence in the system. This implies sufficient health care infrastructures, appropriately staffed and managed, adequate medical supplies including essential drugs and reasonable equity of access. In a health care system based on primary health care, health-related activities at the community level must be considered as integral components of the system.

This latter point is crucial if there is to be success in planning and providing a continuum of HIV/AIDS care. NGOs or voluntary organizations are able to provide comprehensive care for a limited number of HIV/AIDS patients, but others will seek care within the public, organized health care system which should be able to deliver comprehensive care across a continuum of its infrastructure.

Systems must be prepared to provide relief for the wide range of morbidities that present for health care, including infectious, chronic and nutritional conditions. It is important now to identify possible gaps or weaknesses relating to provision of health care for HIV/AIDS?

An efficient referral system

Referral from one level to another is always cited as a vital element in an effective health care system but little effort has been exerted to examine or improve the efficiency of referral systems. An efficiently functioning referral system is a genuine prerequisite for comprehensive health care for HIV/AIDS

Referral of ill patients with HIV/AIDS from their homes to district health centres and to hospital will be made by health centre staff, by community-based service providers and by family care-givers. The problems requiring referral to health centres include sudden onset of fever, diarrhoea and mild dehydration, oral thrush, abscess, and wounds requiring extensive dressings. Conditions requiring referral from home and/or health centres to hospital will include diarrhoea with severe dehydration, pneumonias or chest infections, mental disorders, severe skin manifestations, and malignancies [35].

Attitudes, training/retraining of health care workers

The attitude of health care workers has long been recognised as an important factor in health service utilization patterns. A positive and sensitive attitude is especially important in the care of HIV/AIDS patients who may already face discrimination and stigma outside the health setting. If they are also confronted with negative attitudes when they seek health care, this may represent one psychological burden too many and the final deterrent to using services that are available.

Training and retraining of almost every category of health care staff is critical to increasing HIV/AIDS awareness among them. A higher level of HIV/AIDS awareness among health care staff, particularly at the intermediate health care level, will broaden their recognition of HIV-positive people needing entry into a continuum of care.

Guidelines for clinical management of HIV/AIDS have been formulated at both national and international levels. All appropriate health care staff should be trained or retrained in implementing the guidelines in their health care setting. At the same time, it is important that implementation of clinical management guidelines be monitored in order to help improve or adapt them to the local health care setting. Should this be a specific responsibility of a national AIDS programme?

Training of community health workers is an area for special attention. Most CHWs with roles in community support systems for HIV/AIDS, particularly for home-based care, have for the most part already received training in one or more health areas such as maternal and child health, control of diarrhoeal diseases among children or in immunization programmes. While it is entirely appropriate to retrain them to be able to identify and deal with HIV-related conditions, should they not at the same time be encouraged to be multi-purpose health workers, even in the event that the training/retraining was supported with AIDS resources? Additional training for CHWs should also encompass STD prevention, including access to condom supplies, and possibly overseeing compliance with TB drug therapy regimens.

The credibility of CHWs depends heavily on the support they receive from the health care system, particularly the health centre level. It is thus imperative that the health system be seen as providing adequate training for CHWs in a specific training curriculum and that a careful system of supervision and continuous monitoring is in place and utilised.

Counselling services

Each country needs to define and apply a policy on counselling, particularly in relation to HIV testing. It is generally recommended that pre-test and post-test counselling is given regardless of where the testing is carried out whether it is in a health care facility or in a voluntary testing and counselling facility which may be a "walk-in" site.

Further, anyone who is dealing with knowledge of HIV status should receive training in counselling. This would include many staff in health care settings such as outpatient clinics, blood transfusion centres, facilities set up for assisting with the special problems of injection drug-users, HIV voluntary counselling and testing centres, staff at health centres and district hospitals, tuberculosis clinics and wards, STD clinics and any other environment in which HIV-positive people will be seen. A very important aspect that is often ignored is the lack of private space for counselling especially in public sector health care facilities. Given the issue of confidentiality relating to HIV status this is a circumstance crying out for improvement.

While it is often stressed that counselling should be seen as an additional skill and not as a separate career structure, it is also noteworthy that, in practice, in some countries in Africa counsellors leave government service to seek employment with NGOs. As with any area of trained health care worker, there should be continuous monitoring of the knowledge base and practices of counsellors dealing with HIV/AIDS.

Discharge-referral planner

A recent paper on priorities for HIV testing suggests that until there is improvement in the quality of health care in developing countries HIV testing for diagnostic purposes is generally not appropriate [36].

At least at the hospital level, and most importantly at the district hospital which will usually be nearest the patient's home, there should be a specific focal point for discharge planning for those patients identified as HIV-positive. Without question, many HIV-positive people will enter and leave the hospital setting without ever being identified as such. However, with increasing HIV/AIDS awareness among health care staff larger numbers of inpatients may be offered and may receive HIV testing and counselling. These patients should be seen by a discharge-referral planner to help prepare for further episodes of HIV-related illness and to eventually prepare for home-based care.

Conclusions

There is no doubt that health care services in resource-constrained settings are placed under enormous stress by the additional burden of HIV/AIDS. However, opportunities exist to improve the efficiency and the humanity of care provided to HIV/AIDS even within such settings [37]. Improvements may depend on heavily reinforcing the principles of primary health care and community-based care and on redirecting resources towards the district and the community.

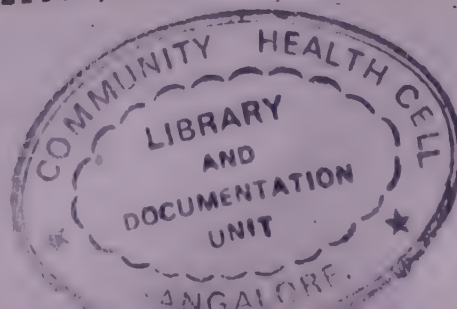
REFERENCES

1. Roemer, Milton I., National Health Systems of the World. Vol. I, The Countries, Oxford University Press, 1991.
2. Better Health in Africa, Report No. 12577-AFR, Document of the World Bank, December 14, 1993.
3. Foster, Susan, Cost and burden of AIDS on the Zambian health care system: policies to mitigate the impact on health services. John Snow Inc. and London School of Hygiene and Tropical Medicine, Londond, UK, 1993 (unpublished).
4. Friesen, H., G. Tembo, D. Odongo, J. Sajjabi & J.B. Kaddu, Report of a survey to assess the care for HIV infected patients at health facilities in Uganda., Draft, WHO/GPA, 1994.
5. Buvé, A., Foster, S.D., Mbwili, C., Mungo, E., Tollenaere, N., Zeko, M. Mortality among female nurses in the face of the AIDS epidemic: a pilot study in Zambia (letter) AIDS 1994, 8:394.
6. Hassig, S.E., J. Perriens et al, An analysis of the economic impact of HIV infection among patients at Mama Yemo Hospital, Kinshasa, Zaire., AIDS 4:883-887, 1990.
7. Gilks, C., A. Adam, L. Otieno, F. Mwongera, M. Amir & J. Paul, HIV infection in acute medical admissions to Kenyatta Hospital: 1988/89 compared to 1992., IX International Conference on AIDS, Berlin, June 1993, [abstract no. PO-B37-2379].
8. Trostle, James & Jonathon Simon, Fieldtesting the manual for group interview techniques in Malawi and Mexico., Final report to WHO Global Programme on AIDS, November 1992.
9. Jackson, Helen & Kate Mhambi, Family coping and AIDS in Zimbabwe: A Study., Journal of Social Development in Africa, 1994.
10. TASO (The AIDS Support Organization. The Inside Story, Draft, 1993-1994.
11. Gilks, Charles F, The clinical challenge of the HIV epidemic in the developing world, Lancet, vol. 342:1037-1039, 1993.
12. GPA promotes continuum of comprehensive AIDS care., Global AIDS NEWS, Newsletter of the WHO Global Programme on AIDS, No. 3, 1994.
13. Guidelines for the Clinical Management of HIV Infection in Adults. WHO/GPA/HCS/91.6, 1991.
14. Guidelines for Clinical Management of HIV Infection in Children WHO/GPA/IDS/HCS/93.3, 1993.
15. HIV Prevention and Care: Teaching Modules for Nurses and Midwives, WHO/GPA/CNP/TMD 93.3, 1993.
16. Report of the WHO Regional Workshop on HIV/AIDS Continuum of Care at the Institutional,

Community and Home Level, WHO/SEA/AIDS/65 1994.

17. Mansfield, Simon & Surinder Singh, Who should fill the care gap in HIV disease? *Lancet*, Vol. 342, September 18, 1993.
18. AIDS Home Care Handbook WHO/GPA/IDS/HCS/93.2, 1993
19. Report of the WHO/Commonwealth Secretariat Regional Workshop on HIV/AIDS Community-Based Care and Control, WHO/GPA/IDS/HCS/92.3, 1992.
20. The Challenge of Implementation. District Health Systems for Primary Health Care. WHO/SHS/DHS/88.1/Rev.1, 1988.
21. Essential Drugs Action for Equity WHO/DAP/92.5, 1992
22. Lunt, R., Economic Impact of AIDS in Uganda. Draft report, World Bank mission, 1991.
23. Lunt, R., Makubalo, Lindiwe E., Msiska, R.M., F. Staugaard, Zambia Health Sector Study, Review of HIV/AIDS Activities. Draft report, The World Bank, 1992.
24. Berezin, N. HIV and other sexually transmitted diseases. Chapter 5 in AIDS in the World, A global report. Ed. Mann J, Tarantola DJM and Netter TW., Harvard University Press, 1993.
25. Over, M. and P. Piot, HIV Infection and STD. In: Disease Control Priorities in Developing Countries, Ed.: D.T. Jamison, W. H. Moseley, A.R. Feachem, J.L Bobadilla, Oxford Univ. Press, 1993.
26. Moses, S. & F.A. Plummer, Health Education, counselling and the underlying causes of the HIV epidemic in sub-Saharan Africa. *AIDS Care*, Vol.6, No.2:123-127, 1994.
27. van Praag, Eric., Integration of STD Prevention and Care Activities into Health Care Systems, Draft chapter for STD Handbook for field workers in developing countries, 1993.
28. Aisu, T., R.C. Raviglione, E. van Praag, P. Eriki, J.P. Narain, G. Tembo, F. Adatu, W. Naamara, Preventive chemotherapy (PT) for HIV-associated tuberculosis (TB) in Uganda: A feasibility study., IXth International Conference on AIDS, June 1993 [abstract no.WS-B09-3]
29. Nunn, P., Elliott, A., Keith P W J McAdam, Impact of human immunodeficiency virus on tuberculosis in developing countries, *Thorax*, Vol. 49, No.5:511-518, 1994.
30. Kochi, A., Programme Manager of WHO TB Programme, Tuberculosis, HIV on Collision Course in Asia, Press Release WHO/63, Yokohama, 10 August, 1994.
31. The Use of Essential Drugs Model List of Essential Drugs (Seventh List), WHO Technical Report Series 825, 1992.
32. Wabitsch, R., Selecting commonly used drugs in HIV/AIDS. Draft, GPA/HCS, 1994.
33. Estimating Drug Requirements: A Practical Manual, WHO/DAP/88.2, 1988.
34. AIDS Drug Estimator: manual and software WHO/GPA/PMT, 1993

DIS-325
4.327



35. Ngugi, Elizabeth, Principal Invesatigator, Feasibility study on integrating community-based AIDS care into government and non-government health systems, Draft generic protocol, August 1994.
36. Colebunders, Robert and Peter Ndumbe, Priorities for HIV testing in developing countries?, Lancet, vol. 342, September 4, 1993.
37. Foster, Susan D., Care and treatment of HIV disease in developing countries from a socioeconomic perspective., AIDS, 8 (suppl 1):S341-S347, 1994.

2

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUT

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



1.1.1288

HIV/AIDS: FIGURES AND TRENDS

Every day, over 7,500 people - nearly half of them women - are newly infected with HIV, the virus that causes AIDS.

As of end-1995, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that some 20.1 million adults are living with HIV/AIDS*, including over 11 million males and almost 9 million females. Heterosexual transmission accounts for more than 75% of all HIV infections world-wide.

Today, the HIV virus is transmitted in all countries and, by the year 2000, UNAIDS projects that 30-40 million people will have been infected.

It is also estimated that over 6 million AIDS cases in adults and children have occurred world-wide since the epidemic began. UNAIDS foresees that this cumulative total will triple by the year 2000. Over 5 million adults and children are estimated to have died from AIDS so far.

1. Population groups particularly at risk

a) *The poor and marginalized*

Poverty is one of the most powerful driving forces behind the spread of AIDS. Today, more than 90% of the more than 20.1 million people alive today with the virus live in a developing country.

b) *Women*

Women are increasingly becoming infected with HIV and at a significantly younger age than men. As of late 1995, almost 9 million women had been infected with HIV since the start of the epidemic. By the year 2000, over 14 million women are expected to have been infected and four million of them to have died.

Why are girls and young women particularly vulnerable to HIV infection? Women are biologically, epidemiologically and socially more vulnerable. For example, women tend to marry or have sex with men older than themselves, who may have had more sexual partners and hence be more likely to have become infected. In some relationships or cultural environments, it is almost impossible for women to insist on protecting themselves against the virus, through mutual fidelity or condom use. In other cultures, men expect sex with any women receiving their financial support.

* includes people who are infected with HIV and who have not yet developed AIDS and those who are infected with HIV and have developed AIDS.

c) Young people

Among both men and women, the hardest-hit group are young people. UNAIDS estimates that half of all infections to date have been in 15-24 year-olds.

In some countries, 60% of all new HIV infections are among 15-24 year olds, with a female to male ratio of two to one among 15-19 year olds.

The belief that sex and AIDS education may encourage sexual activity in young people is a powerful barrier to the introduction of HIV prevention programmes. Yet, there is no evidence to suggest that sex education in schools leads to earlier or increased sexual activity. On the contrary, a number of studies have shown that sex education increases the adoption of safer sexual practices and tends to lead young people to postpone sex.

d) Infants and children

As infections in women rise, so do infections in the infants born to them. Overall, about one-third of babies born to HIV-infected mothers become infected themselves. Perinatal transmission can occur during pregnancy, during delivery, and through breast-feeding. To date, about 1.5 million children have been infected with HIV, of whom more than half a million have already developed AIDS. In addition, UNAIDS estimates that by the end of this century, AIDS will have robbed almost 5 million children of one or both parents.

2. Geographic trends

Currently, Sub-Saharan Africa remains the most affected area. But Asia, where the epidemic is far more recent, is set to overtake Africa as the region with the most new infections.

a) Sub-Saharan Africa

With more than 12.9 million HIV-infected adults today, sub-Saharan Africa is the region hardest-hit. Heterosexual transmission has predominated since the outset and currently the number of women infected outnumbers men by 6 to 5. More than 6 million women of childbearing age have been infected and UNAIDS believes that as many as 1 million children may already have been infected prior to or during birth, or through breast-feeding.

In a number of countries in the region, the spread of HIV has been spurred by population movements due to situations of conflict or poverty. Another contributory factor appears to have been the frequent presence of other sexually transmitted diseases (STDs) which, if left untreated, increase the risk of HIV infection. The lower status of women in a number of cultures has also contributed to the rapid spread.

Recent data suggest that the epidemic is continuing to evolve, particularly in Western and Southern Africa. However, there is also some evidence of a stabilization in HIV infection rates in certain areas of east and central Africa. In one rural district of south-west Uganda, the percentage of those aged 13 and above acquiring HIV infection each year declined from 7.5% in 1989-1990 to 4.5% in 1993. This is attributed to success in changing sexual behaviour.

To date, sub-Saharan Africa has lost more than 3 million people to AIDS.

b) South and South-east Asia

The extensive spread of HIV in South and South-east Asia began in the mid-1980s, but its progression has been very rapid. What is happening in Africa now could be dwarfed by the Asian epidemic.

As of end-1995, UNAIDS estimated that over 4 million people were living with HIV/AIDS in this region. While India and Thailand account for the majority of infections, rapid HIV spread into specific populations in other countries of the region has also been noted.

For the region's adults, the predominant modes of transmission are unprotected heterosexual intercourse and needle-sharing. In some Asian countries, a large proportion of sex outside marriage is not "casual sex" but "commercial sex". One study found that 44% of Thai men had their first sexual experience with a commercial sex worker at an average age of about 18 years. In India, an indication of the population's vulnerability to HIV can be found in the millions of sexually transmitted diseases (STDs) occurring each year.

The AIDS epidemic in South and South-east Asia gained an early foothold among injecting drug users. Today, the virus is spreading rapidly in and around the area known as the Golden Triangle, where most of the world's opium and heroin are produced.

Apart from unprotected sex and drug injection, contaminated blood transfusions also contribute to the epidemic in parts of the region.

c) Latin America and the Caribbean

In Latin America and the Caribbean, over 1.7 million adults are living with HIV/AIDS. Rates of infection are rising in Honduras and in some other Central American countries and in the Caribbean.

Since the mid-1980s, there has been increasing heterosexual transmission, principally among bisexual men and their female sex partners, and among female sex workers and their clients. This is especially true where heterosexual transmission is spurred by a high prevalence of STDs and other genital tract infections, and by social conditions that favour unprotected sex with many partners, frequently as part of a strategy of survival through sex work.

Transmission through drug injecting is also on the rise. In Argentina, for example, HIV prevalence among injecting drug users ranges from 30 to 50%, and in Brazil from 20 to 60%.

d) North America and Western Europe

In this region, over 1.2 million adults are living with HIV/AIDS, including more than 750,000 in the USA alone. The people predominantly affected to date have been homosexual or bisexual men and injecting drug users, together with their sex partners.

However, the transmission of HIV through heterosexual intercourse is on the rise, with especially notable increases in urban populations who have high rates of injecting drug use or STDs.

The USA has by far the highest reported number of AIDS cases in the industrialized world. The proportion of AIDS cases attributable to sexual transmission between men decreased from three-quarters to just over half between 1985 and 1992. However, by 1992, the proportion of cases due to drug injecting had risen to a quarter. HIV infection is, there too, increasingly a

disease of poverty and exclusion, with disproportionately high rates among black men and women.

Since the epidemic started, as far back as the late 1970s, AIDS has become the leading cause of death among adults under age 45 in many US and Western European cities.

In Western Europe, about 450,000 people are living with HIV/AIDS today. There is some evidence that HIV prevalence has stabilized in Northern countries such as Belgium, Germany, the Netherlands, Sweden and the United Kingdom. Switzerland has reported reductions in new AIDS cases. However, the situation is less encouraging in countries such as Spain and Italy.

e) Eastern Europe and Central Asia

In Eastern Europe and Central Asia it is estimated that more than 25,000 adults are thought to be living with HIV/AIDS. While this can still be called low prevalence, this is likely to rise given that the region has many ingredients of rapid HIV spread - economic crisis, rising unemployment, crumbling health systems, ethnic and religious conflicts, the displacement of civilian populations, as well as people on the move in search of economic opportunities.

f) North Africa and the Middle East

The few studies which are available regarding this region suggest that the extensive spread of HIV began in some parts of the Middle East in the late 1980s. As of end-1995, UNAIDS estimates that over 180,000 people are living with HIV/AIDS in this region.

March 1996



Previous Page

3

MATERIAL ON HIV/AIDS

SENT BY

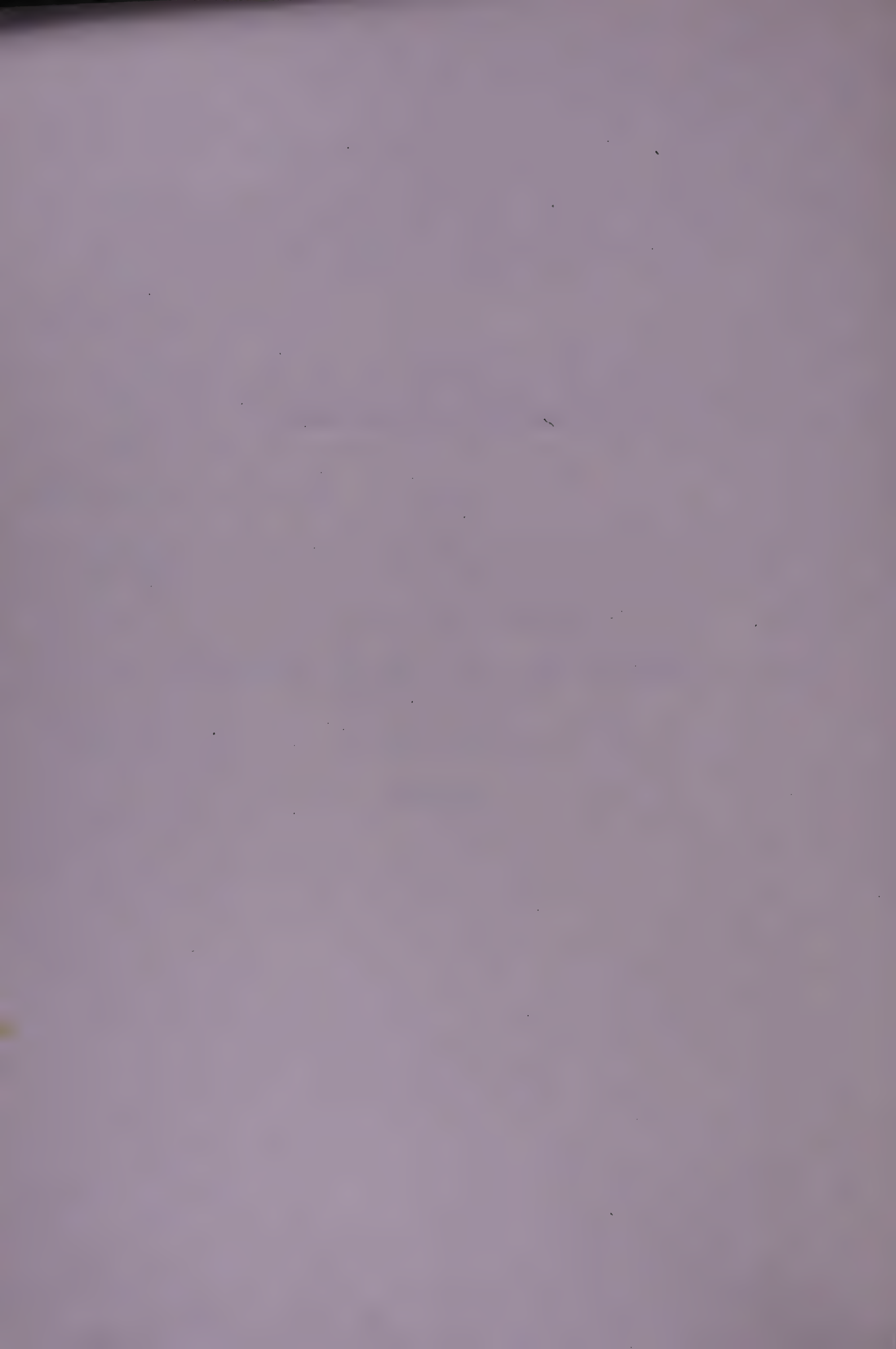
MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



GLOBAL
PROGRAMME
ON **AIDS**

COUNSELLING FOR HIV/AIDS:
A KEY TO CARING

For Policy-Makers, Planners and Implementors
of Counselling Activities



WORLD
HEALTH
ORGANIZATION

TABLE OF CONTENTS

PREFACE	iii
ACKNOWLEDGEMENTS	iv
INTRODUCTION	v
Who is this document intended for?	v
Why is it important to have policies on HIV/AIDS counselling?	v
PART ONE: HIV/AIDS COUNSELLING	1
What is HIV/AIDS counselling?	1
For whom should HIV/AIDS counselling services be provided?	2
What are the main components of the HIV/AIDS counselling process?	6
What are the special characteristics of HIV/AIDS counselling?	7
How is HIV/AIDS counselling related to HIV/AIDS education?	8
PART TWO: POLICY ISSUES IN THE DEVELOPMENT OF HIV/AIDS COUNSELLING SERVICES	11
Why is it important to establish HIV/AIDS counselling services?	11
What factors should be taken into account when developing policies for HIV/AIDS counselling services?	12
What are the goals of HIV/AIDS counselling services?	12
What is the relationship between HIV/AIDS counselling and other activity areas in a national AIDS programme?	12
Where does HIV/AIDS counselling take place?	13
Who takes part in an HIV/AIDS counselling session?	14

Who undertakes HIV/AIDS counselling?	15
How are providers of HIV/AIDS counselling services trained?.....	18
Integrating counselling into existing health services	19
How do HIV/AIDS counselling services link with other services and other agencies?.....	20
Monitoring and evaluation of HIV/AIDS counselling services.....	25
HIV/AIDS counselling for women and children	26
Counselling of adolescents and young people about HIV/AIDS.....	27
HIV counselling and testing	30
How might future developments in AIDS prevention, testing and care affect the delivery of HIV/AIDS counselling services?	30

PART THREE: THE ROLE OF POLICY-MAKERS AND PLANNERS

33

What are the essential policies and procedures that should be in place before HIV/AIDS counselling services are established?.....	33
What steps can be taken to develop appropriate policies for HIV/AIDS counselling?	33
Technical materials and guidelines for HIV/AIDS counselling and related areas	38

Figure 1:	Relative emphasis of different components during a series of counselling sessions.....	9
Figure 2:	Different categories of counselling providers according to level of counselling training and social distance from client	16
Figure 3:	The HIV/AIDS continuum of care	24
Annex 1:	List of WHO/GPA materials on counselling and related areas	40
Annex 2:	Glossary	41

PREFACE

In 1990 WHO published WHO AIDS Series No. 8 *Guidelines for counselling about HIV infection and disease*. This booklet summarized the then current understanding of the subject, including the nature, role, and principles of counselling, psychosocial repercussions of HIV infection and associated conditions, and special situations in which counselling is called for.

However, during the past five years, our understanding of the psychosocial impact of the epidemic has progressed and recommended approaches to implementing counselling should be accordingly modified. For example, reports and observations from countries with experience in HIV/AIDS counselling indicate that, contrary to previous thinking, HIV/AIDS counselling is most feasible when it is focused towards people living with HIV/AIDS and their families, those undergoing voluntary HIV testing and those worried about their risk of acquiring HIV infection. Resources permitting, voluntary counselling and testing services should be made available at easily accessible sites for these individuals. However, it is not an effective intervention for individuals who are not or who do not perceive themselves to be at risk.

This volume *Counselling for HIV/AIDS: A key to caring* contains updated guidance on general policy issues related to HIV/AIDS counselling, with the aim of facilitating the formulation of national policies. The most valuable sources of information in the revision process have been experiences gained by countries providing HIV/AIDS counselling, and the booklet now includes case studies based on these experiences. It reflects the evolution of HIV/AIDS counselling into an essential element in the provision of HIV-related care, and in promoting safer behaviour among those living with HIV/AIDS.

To supplement the guidance to policy-makers that is provided by this publication, GPA is developing two other resource documents. One, *Source book for HIV/AIDS counselling training* (WHO/GPA/TCO/HCS/94.1) focuses on counsellors and their trainers while the other, *Guidelines for implementing HIV/AIDS counselling* (in draft), is intended for managers of health services.

The updated publication *Counselling for HIV/AIDS: A key to caring* comes at a time when much experience has been gained in the training of counsellors and in the actual provision of counselling. Much more has still to be learned about the feasibility of providing counselling services and sustaining them on a large-scale basis, and the impact of counselling activities. The efforts made by governments and NGOs, in the provision of emotional support and care for those affected by HIV/AIDS or those worried about their risk of acquiring infection, should be applauded. This booklet is dedicated to all those who spend time, at work, in the community, or at home, listening to people and talking with them about the individual consequences of being affected by HIV/AIDS.

ACKNOWLEDGEMENTS

WHO wishes to thank Mr Tom Milroy, an independent consultant specializing in planning of health systems and public health policy, for his invaluable contribution to this publication. The organization is grateful to many people living with AIDS, care-givers and AIDS care services managers without whose work the information presented in this book would not have been generated.

Special mention should also be made of the following people who contributed to the 1990 version and to this revised version of WHO AIDS Series No. 8:

- Mr Alfred Chingono, Clinical Psychologist, University of Zimbabwe, Harare, Zimbabwe.
- Dr John Green, Head National AIDS Counselling Training Unit, St Mary's Hospital, London, England.
- Mrs Noerine Kaleeba, Director, The AIDS Support Organization, Kampala, Uganda.
- Dr Gary A. Lloyd, Professor and Coordinator, Institute for Research and Training in HIV/AIDS Counselling, Tulane University, New Orleans, Louisiana, USA.
- Dr David Miller, Clinical Psychologist and Senior Research Fellow, University of Nottingham, England.
- Mrs Riva Miller, AIDS Counselling Coordinator, Hampstead Health Authority, and Senior Social Worker, The Royal Free Hospital, Hampstead, London, England.
- Dr Jan-Olof Morfeldt, President, Noah's Ark-Red Cross Foundation, Stockholm, Sweden.
- Professor David M'Ndeti, Chairman, Department of Psychiatry, University of Nairobi, Nairobi, Kenya.
- Mrs Virginia O'Dell, GTZ, Cameroon.
- Dr John M. Sketchley, Education Adviser to the General Council and Register of Osteopaths, Reading, England.
- Ms Françoise Weil-Hapeva, Psychologist, Necker Hospital for Children and Sick People, Paris, France.
- Mr Tom Milroy, International Adviser, Medicine, Health and Population Division, Universities of England Consortium for International Activities, Sheffield, England.
- Dr Rudolf Bauer, The Gestalt Therapy Institute, Washington, DC.
- Professor Alan Howarth, Department of Psychiatry, University of Zambia, Lusaka.
- Dr Katele Kalumba, Ministry of Health, Zambia.
- Dr Michael Kelly, KARA Counselling Unit, Lusaka, Zambia.
- Dr Jennifer Sosenmsky, HIV/AIDS Counsellor with Durham County Health Department, North Carolina, USA.
- Dr Tom Petersen, CDC Atlanta, Georgia, USA.
- Dr Ron Valdiserri, Assistant Director for STDs CDC, Atlanta, Georgia, USA.
- Ms Joyce S.H. Djaeiani, HIV/AIDS Consultant, Programme for Appropriate Technology in Health (PATH), Jakarta, Indonesia.
- Mr Jon Ungphakorn, Director, AIDS Counselling Center Educational Support Services (ACCESS), Bangkok, Thailand.

INTRODUCTION

Who is this document intended for?

These guidelines are intended to provide **policy-makers and planners** working in health and social service organizations¹ with information to enable them to develop policies that will stimulate, encourage and support the development of appropriate HIV/AIDS counselling services and plan for this service.

This document presents general policy issues in the area of HIV/AIDS counselling. The aim is to encourage countries to develop programme-linked policies and operational guidance for the provision of counselling. It is not intended to give detailed guidance on how to set up and manage HIV/AIDS counselling services or how to design, implement and evaluate training, education or communication programmes. Such guidance is available in other GPA material referenced in the appropriate sections of this publication.

The guidelines are intended to reflect experiences and insights that have been gained in the field of HIV/AIDS counselling since the first version of WHO AIDS Series 8 was published in 1990. As countries develop their counselling services, new ideas and experience will in turn guide the further refinement of services and revision of policies.

Why is it important to have policies on HIV/AIDS counselling?

The existence of sound and clearly stated policies on HIV/AIDS counselling and related areas is central to the establishment of effective counselling services. Policies, in this context, are written guiding principles (including a preferred method of action) issued by the Ministry of Health or other institutions, regarding the provision of HIV/AIDS counselling. Development of policies is particularly important for HIV/AIDS counselling, because

- HIV/AIDS counselling is a recommended prerequisite for HIV testing and, in many instances, HIV testing is a politically sensitive issue. Clear policies are especially important in asserting the role of pre- and post-test counselling.
- HIV/AIDS counsellors, more than any other workers in the field of HIV/AIDS, deal with highly sensitive personal information and with people in their most vulnerable states of mind.

¹ Readers of these guidelines are likely to include:

- members of national AIDS committees
- planning officers
- programme managers
- training specialists
- managers of institutions providing counselling services
- managers of institutions providing training in HIV/AIDS counselling.

The guidelines are also intended for managers, clinicians and others who may occasionally play a role in the policy-making process or have a special interest in HIV/AIDS counselling.

- Carefully devised policies establishing who qualifies to be an HIV/AIDS counsellor are required.
- Within most health and social services, HIV/AIDS counselling is a relatively new activity and, as such, may meet with different reactions from staff and supervisors. In order to avoid serious negative reactions, policy guidance and approval is needed as to the role and scope of this activity.

The guidelines are presented in three parts:

Part One: HIV/AIDS counselling

The aim of this section is to describe the essential features of the HIV/AIDS counselling process. Examples of the potential benefits of good counselling practice are also given.

Part Two: Policy issues in the development of HIV/AIDS counselling services

This section reviews policy issues pertinent to setting up HIV/AIDS counselling services. Brief examples of ways in which counselling services have been established and/or developed in a variety of different geographical, epidemiological and social contexts are given. Several issues regarding HIV/AIDS counselling services, that will need to be resolved by policy makers according to specific contexts, as well as new issues that may arise, are also discussed in this section.

Part Three: The role of policy-makers and planners

This section suggests what steps can be taken by policy-makers and planners to ensure that policies regarding HIV/AIDS counselling are established. Reference is also made to recent GPA publications on HIV/AIDS counselling.

PART ONE: HIV/AIDS COUNSELLING

What is HIV/AIDS counselling?

The Global Programme on AIDS (GPA) defines HIV/AIDS counselling as “a confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour”.¹

GPA recommends that HIV/AIDS counselling services be established to meet the needs of individuals and families who may have HIV-related or AIDS-related problems and concerns.

HIV/AIDS counselling is a process that begins with the client's first contact either with HIV/AIDS counselling services or with the care system for HIV-related needs. In the context of HIV/AIDS, the care system includes all health and social service facilities, both formal and informal, where individuals receive care and social support. The counselling process continues through a referral network to various community and social support agencies according to the needs of the individual and the family affected by or worried about HIV/AIDS.

¹ Further definitions of each of the key words in the GPA definition are as follows:

A client is any person seeking or receiving HIV counselling and/or testing.

A care-provider in the context of HIV/AIDS counselling is any provider who is trained to provide HIV/AIDS counselling services.

Enabling the client to cope with stress, in the context of HIV/AIDS, means:

- providing the emotional support that will help a client to accept the reality (or possibility) of a positive diagnosis of HIV or AIDS of oneself or one's loved one;
- helping the client to identify, explore and select the best options for handling stress;
- helping HIV-positive clients plan for the future by identifying, exploring and selecting available resources in order to meet emotional, medical and social needs that may exist in the life of an individual after a diagnosis of HIV or AIDS.

Facilitation of preventive behaviour means helping the client to identify, explore, select and practise behaviours which will eliminate or greatly reduce the risks of transmission of HIV. This will include helping the client to assess his/her personal risks of transmitting or acquiring HIV and helping the client to plan for a reduction of the risks.

For whom should HIV/AIDS counselling services be provided?

The clients of HIV/AIDS counselling services are likely to be any of the following:

- people with AIDS and their families.
- those who are HIV-positive, and their families;
- those seeking, or agreeing to undergo, an HIV test; and
- those who are concerned that they are at risk or have been at risk of acquiring HIV infection, e.g. those whose partners are HIV-infected or have symptoms of HIV infection, those who may have been exposed through blood, those who have had unprotected sex with multiple partners and those whose regular partners have had unprotected sex with multiple partners.

Box 1. One client's story

He died young and he died with dignity. He was surrounded by his family during his final hours.¹ His workmates visited him regularly right up until the last week of his long illness.

The story had begun several years earlier during a long and arduous business trip. He had visited a bar one evening and had, by chance, met an ex-girlfriend whom he had known while he was a student. They had described their respective lives since they had last met - for example, she told him how she had recently split up with her boyfriend, with whom she had been living for the last two years, because his addiction to drugs was gradually using up all their joint financial resources.

After having several drinks together they had gone to her apartment. They had sex that evening without using a condom.

Several days later he felt pain on urination and noticed a discharge from his penis. He visited a private doctor where, before prescribing an antibiotic for the treatment of his sexually transmitted disease, the doctor gently enquired whether he had considered the possibility that his sexual partner might have been HIV-positive. When he expressed concern that this might be so, the doctor discussed with him several options, including taking an HIV test or not taking a test, but using condoms with his wife. The patient chose to take the test, and the doctor referred him to his colleague who worked in the nearby hospital where an HIV test could be obtained.

¹ Throughout this document the word "family" is used in its broadest sense. Depending on the specific context, "family" may therefore include:

- those living in a committed relationship with the client;
- those living in the same household as the client;
- important members of the client's extended family or community.

When he nervously arrived at the hospital, the doctor there greeted him warmly and referred him to have a conversation with one of the nurses in her office. In the course of the conversation, the nurse asked him why he wanted an HIV test. She listened carefully as he explained his recent sexual history and described his fears. She then asked him what actions he might take if the result of the HIV test turned out to be positive. They also discussed what it would imply to be HIV-positive and what he would do in the interim to protect his wife in case he was already HIV-infected. The patient finally felt prepared to take the test and a blood sample was taken.

Several days later, he returned to find out the results of his HIV test. When the nurse told him that it was "negative" he was overjoyed. The nurse described "the window period"¹ and suggested that it would be advisable to take another HIV test in four or five months and to use a condom for all sexual contacts. However, since it was inconvenient to come to hospital when one was not ill, they agreed that it might be better to take the next test at the anonymous HIV testing site in the capital city.

After almost six months, he travelled to the capital, where there was a walk-in counselling and testing centre that provided HIV tests on an anonymous basis. After a short wait, during which he read about HIV and AIDS in some of the booklets that were available in the waiting-room, he was greeted by a social worker and taken to an office where he and the social worker reviewed the reasons why he had come for an HIV test. They also discussed what action he might take were he to be HIV-positive and he explained how he had a young family who were dependent upon him. He was then directed to the laboratory where a blood sample was drawn.

Five days later he returned to the counsellor's office to receive his test result. The care-provider calmly informed him that the test result indicated that he was HIV-positive. On expression of doubt, the counsellor further explained that there was almost no chance that a mistake had been made. For a while he did not respond: he felt he might lose his senses. When she tried to explain to him that this did not automatically mean that he was about to die, he could not understand. He remembers that she began to plan with him where he would spend the night and what he would do for the next 24 hours until he came back to see her the next day. By the end of the session the client had come to the point of agreeing to return the next day to discuss what the next steps might be. That night he slept in a hotel in the city.

When he returned the next day, he was still distraught. He stated that he feared to return home because he could not face seeing his wife and family. He and the counsellor listed and evaluated all the possible options as to what he should do next. Eventually, after a long discussion of all the options, during which the counsellor listened carefully to all that he had to

¹ The window period is the period between acquiring HIV infection and the appearance of HIV antibodies that can be detected by HIV antibody tests. During this period, individuals are already infectious but their blood tests are HIV antibody negative.

say, he decided that it would be best if he brought his wife to the next counselling session and that the care-provider would be available to help him to break the news.

Before he left her office that day, she asked him to describe how his wife might react; then they did some role-plays in which the care-provider played the role of his wife as he rehearsed how he would break the news. Eventually he gained confidence that with the help of the counsellor he would be able to find the best way to tell his wife.

Because of the preparations that he and the care-provider went through, the counselling session where he told his wife that he was HIV-positive was, in relative terms, a success. His wife accepted to be tested for HIV and luckily she was HIV-negative. After a discussion with the counsellor, the couple decided to use condoms consistently.

The client's next major hurdle was to decide whether he should request his other sexual partner to visit the counsellor with him. After considering all the options, he decided that this was an appropriate step to take and, as a result, she came to the next counselling session during which he informed her of his HIV-positive status. She subsequently decided to receive counselling and eventually opted to have an HIV test which turned out to be positive.

The counsellor (in the city) then referred them to a community-based AIDS support organization in the township where he worked. The counsellor at the organization continued to provide counselling and support to the couple whenever they came in to see her.

During subsequent counselling sessions, in consultation with the counsellor, the client listed and evaluated all of the options for tackling each of the many other problems, both actual and potential, that now faced him. The final product was a comprehensive plan for making sure that his wife and children would be protected from HIV infection and would be adequately provided for when he died. At every step he presented his ideas and plans to his wife and discussed them in detail with her.

It was at work that the client faced his next major challenge. He had noticed, in conversations with his colleagues, that there was a great deal of potential for discrimination against those who are HIV-positive. After discussing this with the HIV/AIDS counsellor, he decided to bring up the subject with the members of the AIDS support organization. They suggested that he should bring up the subject with the nurse at his workplace, who had been trained in HIV/AIDS counselling. He did this, and together they developed a strategy for educating the workforce about HIV and AIDS. The resultant changes that took place in some of his colleagues after a series of difficult and highly emotional discussions gave him the confidence to finally inform them that he was HIV-positive. Not only did they provide him with social support over the coming years, but several of them became active as volunteers in various local organizations that had been set up to combat AIDS.

Throughout the next six years he received varying amounts of ongoing supportive counselling and social support. His wife attended many of these sessions and they continued to

work together in confronting the many challenges of AIDS. Whenever he was most sick, a team of care-providers visited him regularly at his home, and one member of the team played a major role in supporting him emotionally during the most difficult times. Eventually he became very ill and was taken to hospital, where a hospital-based religious worker took over some of the role of providing emotional support to him and his family. Throughout this period, his colleagues at work and members of a local voluntary organization met many of his material needs.

The client's story in Box 1 illustrates a combination of elements of HIV/AIDS counselling and a range of skills which the care-providers put to use in order to support the client and to facilitate preventive behaviour:

- At the private doctor's office, the doctor tactfully enquired about the risks of HIV transmission to which the client had been exposed and presented him with a list of the options regarding what he should do about it, and where he might obtain an HIV test and under what circumstances.
- At the local hospital, the nurse, who had attended a training workshop on HIV/AIDS counselling, helped him to begin to prepare for the possibility that he might be HIV-positive and that he might have to live with HIV infection. This counselling eventually helped him to absorb the shock of the news that he was HIV-positive.
- At the local hospital again, after informing him of the negative results of his HIV test, the same nurse informed him about "the window period". Had she not done this, he almost certainly would never have returned for a second test and would not have become aware of his HIV status in time to be able to learn how to prevent further exposure of his wife to HIV.
- At the anonymous walk-in counselling and testing centre in the capital city, the counsellor presented him with the results of his second HIV test and helped him to come to terms with the initial shock of the news that he was HIV-positive. Had there been no one to support him and to listen to him at this critical time, he might have been unable to cope with the news or might have behaved in a destructive manner such as deliberately spreading the virus.
- At subsequent counselling sessions, once he had come to terms with the reality of his HIV status, the same trained counsellor helped him to consider different options and to make the decision that he must tell his wife that he was HIV-positive and must tactfully request his other sexual partner to visit the counsellor with him so that she too could have the opportunity to receive HIV/AIDS counselling and care. The counselling provided to him and his wife enabled them to know and accept their discordant HIV status and to decide to use condoms.
- At the workplace, the nurse discussed with him the advantages and disadvantages of informing his workmates that he was HIV-positive. As a result of this discussion, he eventually decided not only to inform his workmates of his HIV status, but also to play a role in HIV education. His educational efforts led to changes of attitude to HIV-positive persons amongst

- his co-workers and this, in turn, meant that his colleagues were available to provide him with social support at critical times during his illness.
- At his home, a social worker on the home-based care team provided him and his wife with ongoing supportive counselling that helped them to cope with the many crises that had arisen during his long illness.
 - At the hospital, religious workers not only attended to his spiritual needs but also helped him to make practical preparations relating to the material and spiritual needs of his wife and children after his death.

In addition to counselling, individuals affected by HIV/AIDS need to receive **social support** from workmates, from members of their family, from members of local voluntary organizations that provide social support for people in need and from members of specific AIDS support organizations that communities may initiate.

What are the main components of the HIV/AIDS counselling process?

The two main components of HIV/AIDS counselling sessions, are:

- the provision of **emotional support**, including helping the client to cope with stress and plan for the future; and
- the **assessment of risks and planning for risk reduction**, including the development of decision-making capacity about options for prevention.

These are supplemented, as necessary, by personalized **information-giving**. For example:

- A health worker who expresses the fear that he or she is at risk of acquiring HIV in the work setting may, as part of the counselling process, be provided with scientifically-based information that:
 - * confirms that these fears are a logical response and are not abnormal. Such information is reassuring to the client and can assist in the process of providing the client with emotional support;
 - * informs about risks of HIV transmission from various medical procedures. Such information is provided to help the client plan ways of minimizing the risk of being infected with HIV.
- A person with multiple sexual partners who is considering ways of changing his or her behaviour may:
 - * be provided with scientifically-based information regarding the extent to which abstinence, mutual fidelity or the consistent use of condoms may reduce the risk of HIV transmission and about ways in which

condoms should be used if they are to be effective in preventing HIV transmission.

- * be told that the risk of becoming infected with HIV increases with the number of partners and encouraged to reduce the number of partners.

The relative emphasis placed on each component of HIV/AIDS counselling during a counselling session is determined by the client's particular needs at that time and by the client's readiness to confront the issues that are associated with HIV. Therefore, the well-trained and perceptive care-provider, based on the client's needs, will decide on the relative "weighting" of the two main components of counselling on a session-by-session basis. For example:

- During a counselling session, when a client is first informed of a diagnosis of HIV infection, almost all the emphasis is likely to be placed on the provision of emotional support and on helping the client to come to terms with the consequences of the information that he or she is HIV-positive. Without this emphasis on providing emotional support during the post-test counselling of HIV-positive clients, it is unlikely that the client will subsequently be able to absorb and respond to the risk reduction element of counselling (including, for example, notification of sexual partners of the client's HIV-positive status).
- During a counselling session that takes place after the client has begun to accept and come to terms with the fact that he or she is HIV-positive, it may be more appropriate to place more emphasis on risk assessment and planning of risk reduction. This will enable the client to make appropriate decisions, for example, regarding how to prevent transmission of HIV to his or her sexual partners (or to those sharing needles with the client).

In the particular case of the client whose story is described in Box 1, the relative emphasis of each of these components in the series of counselling sessions involved is shown in Figure 1.

What are the special characteristics of HIV/AIDS counselling?

In order to achieve the objectives of providing emotional support and facilitating prevention behaviour, HIV/AIDS counselling needs to:

- be a **confidential** and personalized process unless and until the client decides otherwise;¹

¹ Confidentiality in HIV/AIDS counselling implies that only the client and the providers involved in direct care of the client have access to the client's personal information. This information is not furnished under any circumstances to other health care providers, health authorities, family members, employers, insurers, schools or other third parties without the patient's explicit consent.

- **react to the client's needs** and involve conversation and dialogue, without being a didactic process;
- be an **empowering and enabling** process which results in clients taking full responsibility for making those decisions that will directly affect their lives or those of members of their families.

How is HIV/AIDS counselling related to HIV/AIDS education?

HIV/AIDS counselling and HIV/AIDS education have much in common, such as their joint dependence on the ability of the provider to communicate effectively, their role in providing accurate information on HIV prevention and care, the need to be culturally sensitive and the need to assess the knowledge of the receivers before communicating.

The major distinction is that HIV/AIDS counselling is a confidential communication made in response to the needs of the client, providing emotional support to individuals and families who may have HIV-related problems and worries.

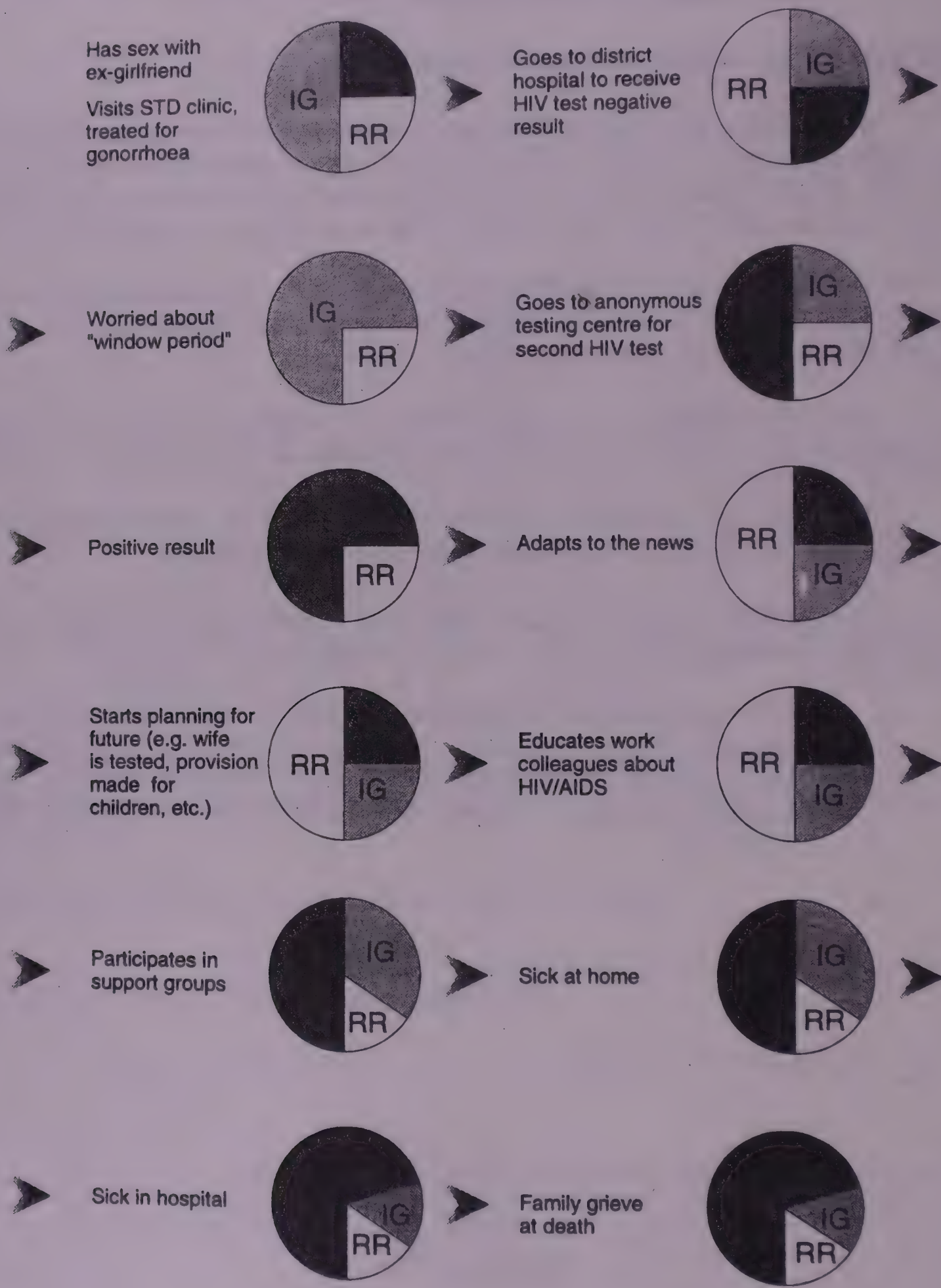
HIV/AIDS education, on the other hand, is a communication that is not usually confidential, is designed in accordance with public health needs and provides information.

The basic skill involved in HIV/AIDS counselling is personalized one-to-one communication relying heavily upon conversational and listening skills.

Educational activities similarly need skills in interpersonal communication but are not necessarily confidential and not geared towards the provision of emotional support:

- HIV/AIDS education, including peer education and one-to-one education;
- communication during clinical and nursing care of AIDS patients and of other patients worried about their risk of acquiring HIV infection; and
- community education and empowerment to make community decisions about HIV/AIDS

Figure 1: Relative emphasis of different components during a series of counselling sessions
(ES = emotional support, IG = information-giving, RR = risk reduction)



In summary

HIV/AIDS counselling:

- is a dialogue aimed at enabling the client to make personal decisions relating to HIV/AIDS;
- is provided to those affected by HIV/AIDS, those seeking or agreeing to receive HIV testing and those worried about their risk of acquiring HIV infection;
- consists of emotional support, personal risk assessment and planning for risk reduction, and is supplemented by personalized information-giving;
- differs from health education in that counselling is targetted primarily towards meeting individual clients' emotional needs and is confidential.

PART TWO: POLICY ISSUES IN THE DEVELOPMENT OF HIV/AIDS COUNSELLING SERVICES

Why is it important to establish HIV/AIDS counselling services?

HIV/AIDS counselling services are established with the goal of meeting the expressed needs for emotional support of individuals who may have HIV-related problems or concerns. HIV/AIDS counselling is a responsive service that should be available to meet the needs for emotional support that are expressed by individual clients.

HIV/AIDS counselling services are important not only for individual clients and their immediate family but also for the community that immediately surrounds the client (including friends and co-workers). In the long run, when affected individuals and families are supported to cope with the effects of and worries about HIV/AIDS and helped to come to terms with the diagnosis, they can talk more openly about their problems to selected members of the community who may provide some help. The wider community benefits through the maintenance of the social fabric and HIV/AIDS counselling tends to have a "ripple effect" on the community.

HIV/AIDS counselling is important for **individual clients** because:

- it helps HIV-positive clients to cope with news of their HIV status and related feelings, develop self-esteem and live productive lives, as well as to seek medical and social support;
- it helps individuals to assess their and their partners' risk of becoming infected with HIV and make plans to reduce the risk.

HIV/AIDS counselling is important to **those who are closest to the client**, such as family or close friends, because:

- it facilitates communication between a client and the family;
- it enables the client's family to be involved in discussions of what measures will be taken to provide care for the client and to prevent transmission of HIV infection.

For these reasons, national AIDS programmes are urged to develop policies that will facilitate the development and implementation of appropriate HIV/AIDS counselling services as part of other HIV/AIDS-related activities.

What factors should be taken into account when developing policies for HIV/AIDS counselling services?

HIV/AIDS counselling will differ from place to place depending on a variety of factors. Planners should take stock of these factors in their local context before developing policies on HIV/AIDS counselling services. Factors which should be taken into account in establishing HIV/AIDS counselling services include:

- **epidemiological factors** such as the current prevalence of HIV infection, its distribution amongst particular groups, and trends in HIV transmission;
- **sociocultural factors** such as current attitudes to HIV/AIDS amongst key groups such as policy-makers, care-providers and community members;
- **historical or political factors** such as the existence of legislation and policies relating to mandatory testing and notification of infectious diseases or the results of any evaluations or assessments of health services;
- **service-delivery provisions** such as the current distribution of health, family planning, counselling and social service facilities and related manpower and the rationale for, and appropriateness of, this distribution.

What are the goals of HIV/AIDS counselling services?

Policy-makers and planners in a country or institution should define the goals of HIV/AIDS counselling services as a guide to implementors.

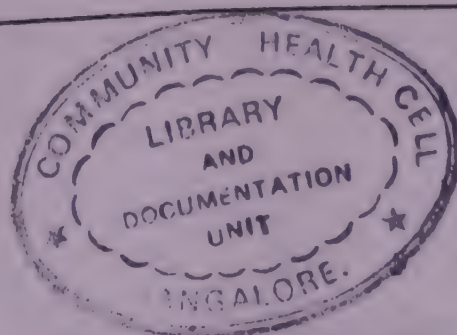
In the context of a national AIDS programme, the two goals of counselling are usually:

- (1) To reduce emotional stress and enable people living with HIV/AIDS and their families and those undergoing linked HIV testing to cope.
- (2) To make possible personal confidential risk assessment and to facilitate preventive behaviour for those worried about their risk of becoming infected with HIV and for those living with HIV.

What is the relationship between HIV/AIDS counselling and other activity areas in a national AIDS programme?

HIV/AIDS counselling has a mutually reinforcing relationship with each of the other activity areas in a national AIDS programme. For example, HIV/AIDS counselling positively influences:

- **HIV/AIDS education and information-giving services**, by removing some of the emotional barriers which may impede learning and may also prevent subsequent behaviour changes from taking place. Counselling makes



DIS 345
14327

educational messages more personally relevant as a follow-up to an HIV education campaign. In turn, education and information benefit HIV/AIDS counselling by making clients aware of the availability of HIV/AIDS counselling services and by explaining the role of such services.

- HIV/AIDS **clinical management and clinical care** services, by enabling the client to participate in decision-making regarding different options for care, such as choosing between hospital and home care after consideration of their relative costs, inconvenience to the family and potential benefits. In turn, clinical management services benefit counselling by reducing the physical symptoms of clients, such as persistent diarrhoea, so that clients regain a sufficient level of self-esteem and physical health to enable them to participate in decision-making and planning.
- **social support** services, by encouraging and enabling clients to identify and express their needs for support, thus helping clients to discuss various options. In turn, social support benefits counselling by meeting the clients' needs for material resources, thereby enabling the counsellor to concentrate on meeting the clients' needs for emotional support.
- HIV/AIDS-related **community development and community organization** activities, by stimulating more open and informed discussion of HIV/AIDS and of the role that community members might play in care and prevention programmes. This happens when counselling enables individuals and families affected by HIV/AIDS to come to terms with the diagnosis so that they can talk more openly about their problems to selected members of the community who may provide some help. This concept which starts with individual clients can then, through the "ripple effect" of counselling, spread to the wider community. Counselling benefits from community development and the activities of community organizations through the provision of locally available resources and expertise which may often be voluntary and therefore low-cost.
- the **societal response to AIDS**, by providing models of compassionate and informed behaviours that are responsive to the dilemmas and difficulties stemming from the AIDS pandemic.

Where does HIV/AIDS counselling take place?

HIV/AIDS counselling takes place in a wide variety of settings. Regardless of the existing HIV prevalence in a country or region, counselling services should always be available at:

- sites where care is being provided for HIV-positive persons; and
- sites where HIV tests are done and results can be traced to the individual (linked HIV testing).

In countries, or in defined geographical areas within a country, where HIV prevalence is high, HIV/AIDS counselling services should **also** be available at the following sites :

- community sites where ongoing support is provided to those affected by HIV/AIDS;
- health clinics at the workplace; and
- independent sites where voluntary counselling and testing can be sought.

Who takes part in an HIV/AIDS counselling session?

Most HIV/AIDS counselling sessions are confidential and most involve the participation of a single client and a single care-provider. The client has an absolute right to confidentiality and/or anonymity unless and until he or she decides otherwise. However, at the discretion of the client and the care-provider, the following other people may be involved in an HIV/AIDS counselling session:

- members of the client's family;
- a second care-provider with additional counselling skills which may be required to help the client address a particular problem;
- other resource person such as a clinician, a co-worker or religious leader.

Counselling clients in a group can be less time-consuming and therefore less costly than counselling individual clients. However, the circumstances under which more than one client attends a counselling session are subject to careful consideration. The use of group counselling is probably most appropriate at those stages of the counselling process when the educational element is paramount. Group counselling is not appropriate when the emotional support element takes precedence (for example, at a counselling session when a client is to be informed of the positive result of an HIV test) and/or when confidentiality is required.

Because of the greater potential for breaches of confidentiality when group counselling is being undertaken, clients should always be given the opportunity to give their fully informed consent before participating in a group counselling session. Secondly, selection of group members should be sensitive to age, gender and sexuality differences among potential group members. Female sex workers may not find it easy to be in the same group as married women; men who have occasional sex with other men may not relate well with men who identify as gay; men who never have sex with men will relate even less well; and street children may not be understood by moralistic adults.

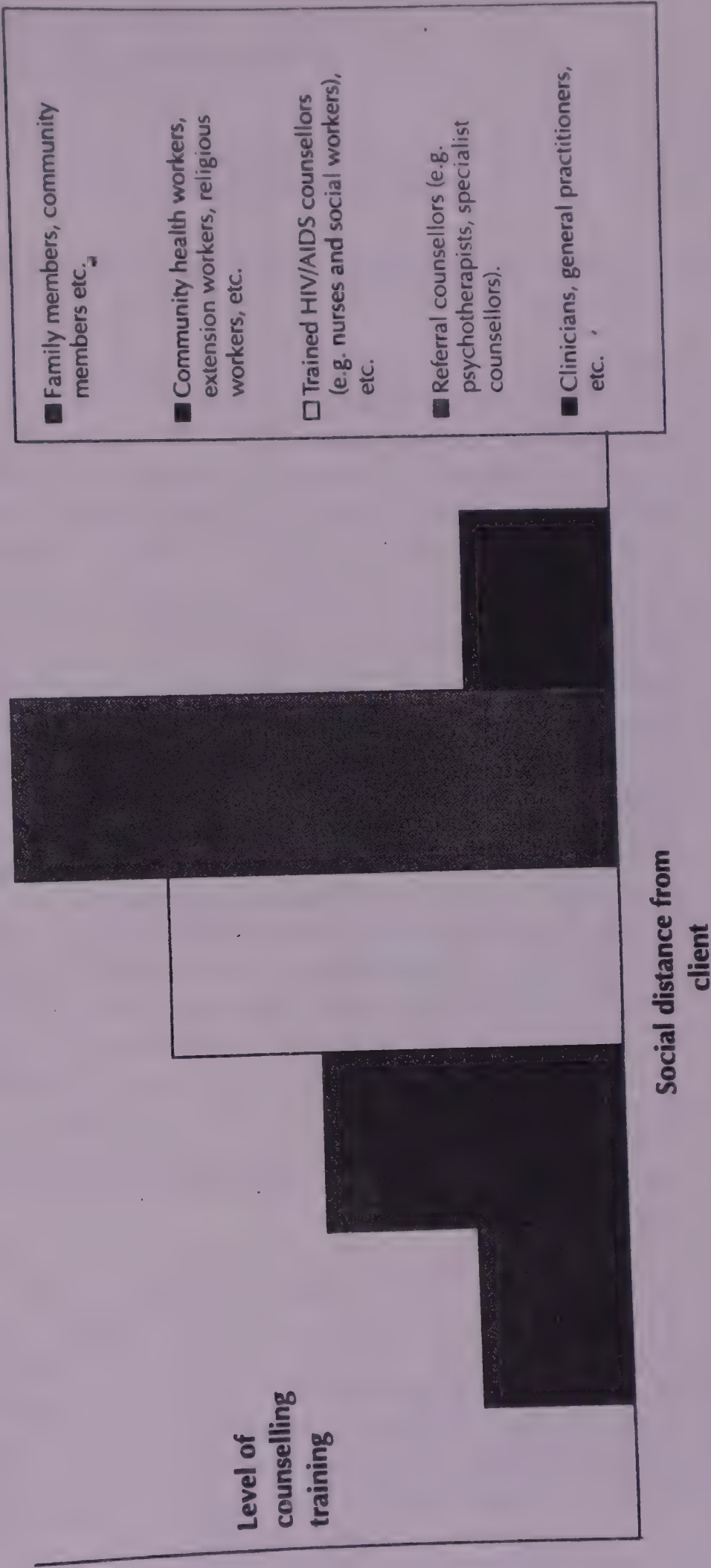
Who undertakes HIV/AIDS counselling?

A wide range of people may play a role in the provision of HIV/AIDS counselling services. They may include:

- nurses, social workers and other care-providers who have been specially trained in HIV/AIDS counselling and who may be either part-time or full-time providers of counselling services at facilities in their country. Some of these trained individuals may also act as "focal points" for counselling services in their country, province or district;
- full-time counsellors (e.g. psychologists and therapists) who have been trained in HIV/AIDS counselling and who may receive clients directly or through referral by other care-providers;
- religious workers and other community-based workers whose work consistently entails the appropriate handling of confidential information and emotional issues;
- community members, and members of AIDS support organizations and people living with HIV/AIDS.

The level of counselling training and the social distance of each of the above categories of care-giver will vary greatly from setting to setting. Figure 2 is an illustration of such variations among different providers of counselling.

Figure 2: Different categories of counselling providers according to level of counselling training and social distance from client



Counselling services are commonly provided by nurses or social workers who have received practical training in HIV/AIDS counselling. A cadre of specialist counsellors may be available for referral or consultation purposes - these will often be trained psychologists, psychotherapists or social workers and nurses who have received specialist training and have gained extensive experience in HIV/AIDS counselling.

Some examples of appropriate patterns of counselling responsibility in different settings are given below:

1. In a setting where HIV prevalence is low, but where the degree of stigmatization against HIV-positive persons is high, there may be a need for a cadre of trained care-providers who can provide the greater emotional and social support that is likely to be necessary for HIV-positive clients in such settings. The role of trained care-providers, such as nurses and social workers, in HIV/AIDS counselling in these settings is likely to be large, whereas the counselling role of peers and community-members at this stage in the development of the epidemic may be less. In such a setting, community members may be trained as peer educators rather than as counsellors
2. In a rural setting where HIV prevalence is high, but where potential clients of counselling services do not have access to health care facilities, more participation of community members in the HIV/AIDS counselling process, usually with leadership and training from relevant counselling organizations that have a presence in the area, may be the only possible way of meeting the need for HIV/AIDS counselling. If HIV prevalence in such settings is particularly high and if the very limited number of overburdened health care workers are unable to take the lead in organizing the provision of counselling services, the community itself may need to take on additional responsibility for organizing and providing counselling services as well as for providing care to AIDS patients.
3. In a setting such as a large city where per capita incomes are relatively high, services for those who can afford them may be provided on a private basis by psychologists and therapist who have developed expertise in HIV/AIDS counselling. Alternatively, if funds are available from the public sector, they may provide services in the public sector whilst providing private services in their spare time, or vice versa.

AIDS "hotlines" have been established in several countries. The main goal of these services is to provide accurate information about HIV/AIDS and, if necessary, to refer clients to trained HIV/AIDS counsellors or HIV counselling and testing centres. Under certain circumstances, clients may request that HIV/AIDS counselling services be provided by telephone. The provision of telephone counselling services is important in settings (where telephone services are widely available) where some clients may have realistic fears about retaining anonymity or where access to face-to-face counselling services is difficult. In any case, telephone counsellors should have previous training and experience as HIV/AIDS counsellors and this should be supplemented by training as telephone counsellors. The giving

of HIV test results by telephone should be discouraged. Box 2 illustrates an example of anonymous counselling provided by means of a "hotline".

Box 2. The AIDS hotline: anonymous counselling

Peter left home at the age of twenty and moved to the city. This was a liberating experience for Peter, who had known for several years that he had a sexual preference for other men. His formative years had been spent in an environment where intense stigmatization against those who practised a homosexual lifestyle and against those who might be HIV-positive was the norm. Soon after he arrived in the city, he established a permanent relationship with another man with whom he lived in a committed relationship for the next six years. During these six years, Peter never communicated with his parents, who did not even know where he was living, because he knew that his father, a senior military officer, would be appalled by the fact that he was living with another man.

During these six years, several friends of Peter and his partner became HIV-positive. Peter started to worry that he too might be HIV-positive. However, since he was well aware of the high level of stigma towards homosexuality, he was reluctant to meet any health officials in order to discuss this risk. He was delighted to learn of the availability of a telephone hotline, through which he could discuss his HIV worries without being identified. After discussing his sexual history over the telephone with a staff member of an AIDS hotline, Peter decided to go for an HIV test at a local counselling and testing centre where he was assured of receiving an anonymous HIV test. The result of the test was positive.

The counsellor who gave him the news of his HIV-positive status provided Peter with emotional support and then referred him to a counselling service, and to an AIDS support organization, that were both nearer to his home. After several months of counselling, and as a result of considering all of the options that were presented to him by the counsellor, Peter decided to make contact with his parents again.

How are providers of HIV/AIDS counselling services trained?

The design of training programmes is based on the specific objectives of counselling service provision in a particular setting and on the pattern of service delivery that is most appropriate for meeting these objectives.

Effective training of providers of HIV/AIDS counselling services always has a closely-supervised practical component. Therefore, counselling training programmes should be designed in such a way that ample opportunity is provided for trainee counsellors to receive this practical training and to learn by sharing their experience with the help of a supervisor.

GPA has published the *Source Book for HIV/AIDS Counselling Training* (WHO/GPA/TCO/HCS/94.1) from which those who plan and/or conduct training for HIV/AIDS counselling service-providers can extract material and adapt it to the needs of the trainees at hand (see Annex 1). Some countries or institutions may then use this adapted material to develop their own counselling training manuals. These manuals can be used by those who have gained expertise in HIV/AIDS counselling to train other providers in counselling skills as the need arises.

Integrating counselling into existing health services

HIV/AIDS counselling is a labour-intensive activity that will consume a significant portion of the already overstretched time of health or social workers. Service planners will need to develop strategies for integrating this new service into existing ones so that counselling is not seen as an extra burden, but rather as a support to other services.

Strategies for integrating HIV/AIDS counselling services include:

- **redefinition of job descriptions** of carefully selected staff so that HIV/AIDS counselling becomes an added role without creating a new post. In many settings, especially those where HIV prevalence is high, this has been done for those cadres of nurses and social workers who are to be trained in HIV/AIDS counselling. If this approach is adopted, great care should be taken to ensure that other essential services do not suffer.
- **involvement and training of volunteers** to provide services. This method has been applied particularly in those countries where there are social workers, school teachers, religious workers, PWAs and other community members who are willing to donate a portion of their time to provide HIV/AIDS counselling services on a voluntary basis. These volunteers have been especially useful in providing on-going community-based counselling to individuals referred to them from the formal health and social services.
- the selection and testing of innovative **alternative approaches** to counselling that may allow a reduction in the staff time required. If this approach is adopted, great care should be taken to ensure that the essential features of the counselling process are not compromised. Careful attention should also be given to ensuring that any alternative approaches that are selected still allow for the necessary interaction and dialogue between the client and the care-giver. This dialogue is the fundamental component of the counselling process. For example, videocassettes, leaflets and group information sessions have been used to provide the bulk of information needed by clients, before they meet the counsellors, so that the counselling session can be shortened. If any of these are used in a supplementary role, their use should be carefully integrated into the ongoing counselling process by a trained counsellor.

- **written procedures for the provision and organization of HIV/AIDS counselling services.** The presence of standard procedures will facilitate supervision and monitoring by making it clear what is expected of the staff of a counselling service. They will enable other staff to know when and where to refer clients who need counselling. Clear procedures on how HIV-related client information is handled will enable high standards of confidentiality to be maintained while at the same time allowing information to flow. In the long run, when staff know what to do and when to do it, staff stress will be minimized.

Boxes 3 and 4 provide examples of how some countries have developed counselling services to respond to the identified needs of their communities.

How do HIV/AIDS counselling services link with other services and other agencies?

For many individuals needing and/or seeking HIV/AIDS care, counselling represents one of the entry points to care. This is true for a client who comes to a walk-in HIV testing centre and requires pre-test counselling, as well as for the client who comes to the health centre with symptoms of AIDS and is referred to a trained counsellor who is responsible for breaking the news that the client has AIDS. The level of trust between the client and the caregiver created during the initial stages of the counselling process will often be a critical determinant of later relationships between the client and the variety of individuals and organizations that play a role in the provision of care, including counselling. The various interactions between the individual and different caregivers within a comprehensive care system are shown in Figure 3.

Some organizations and services which may have links with counselling services are:

- **clinical management services.** For example, a client who receives the information from a counsellor that he or she is HIV-positive may be referred by the counsellor to a clinician who specializes in the care of HIV-positive patients. Similarly, an individual who learns that he or she is HIV-positive may need the help of a counsellor to liaise with clinicians in other specialized clinics, e.g. haemophilia clinics or antenatal clinics, where information about HIV status may be needed but has to be passed on in a confidential manner.
- **family planning services.** For example, an HIV-positive client who wishes not to become pregnant for fear of transmitting the virus to her unborn child, may be referred to local family planning services to obtain contraceptive services and counselling.

Box 3. Country counselling services, Zambia

In order to respond to the great numbers of individuals needing HIV/AIDS counselling, the National AIDS Programme of Zambia has supported the countrywide development of counselling services using existing health and social workers in the following ways:

- a national "focal point" for HIV/AIDS counselling, whose role is to coordinate all HIV/AIDS counselling activities, including the policy development process, has been designated;
- a countrywide programme of training in HIV/AIDS counselling for clinical officers and nurses has been implemented and plans are being developed to set up counselling services as an integral service in all district hospitals;
- advanced training in HIV/AIDS counselling has been provided for carefully selected staff from each Province who can receive referrals from other counsellors and conduct training in HIV/AIDS counselling;
- a walk-in counselling and testing centre, staffed by full-time HIV/AIDS counsellors and providing anonymous testing and counselling, has recently been opened in Lusaka, the capital city;
- mobile teams of trained HIV/AIDS counsellors take their services to workplace settings where counselling services are available as an adjunct to educational programmes about HIV/AIDS;
- members of home-based care teams who visit AIDS patients in their homes (as part of a national policy to make home-based care services available and thereby reduce the number of hospital inpatients) have been trained as counsellors;
- "group counselling" has been introduced at carefully selected phases of the HIV/AIDS counselling process in order to provide some of the educational elements of the HIV/AIDS counselling process at lower cost;
- peer education interventions that are closely linked with HIV/AIDS counselling services and that make increasing use of the contributions of HIV-positive individuals have been introduced;
- counselling services with staff members who are trained in HIV/AIDS counselling to supplement their training in generic counselling skills have been established in the university and in other institutions of higher education.

Box 4. Country counselling services, Myanmar

In Myanmar, the prevalence of HIV infection is high among individuals who are injecting drug users (IDUs) and among commercial sex workers. Initially, many cases of HIV were discovered among blood donors. A surveillance team was formed to follow up these HIV-infected individuals and advise them about prevention of HIV transmission. This team of health workers soon discovered that, whenever they visited the HIV-infected individuals, they had to deal with a variety of emotional and social issues before they could get the HIV-infected individuals to listen to advice about prevention. These emotional and social issues included:

- rejection by the spouse and family and even being thrown out of the house;
- not knowing how to inform their partners and families about their HIV status;
- being ill but reluctant to go to the hospital for fear of being identified as HIV-positive and subsequently being subject to stigmatization.

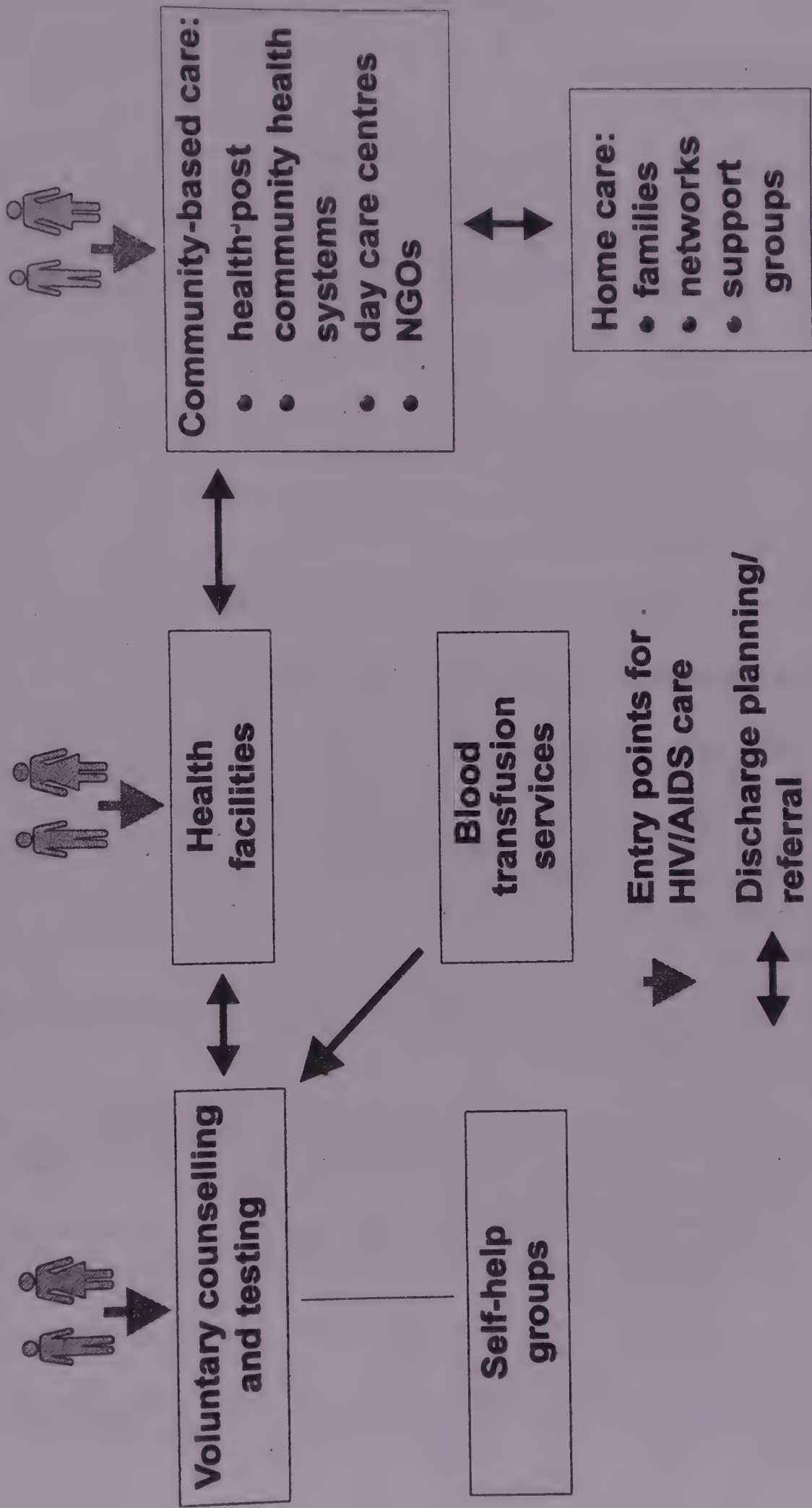
In the Drug Detoxification Unit of Yangon, where IDUs are admitted to be detoxified and rehabilitated, nearly 60% of the patients are HIV-positive. While the medical social workers at these units were well equipped with knowledge and skills to advise IDUs to stop using drugs, the emergence of HIV raised new issues to be considered. In addition to the issues highlighted above, the medical social workers had to address the following:

- options for prevention of HIV transmission among IDUs did not/were not able to stop injecting;
- how best to tell the family that a person is injecting drugs and is infected with HIV.

Faced with these challenges, the National AIDS Programme requested technical assistance from WHO/GPA to train members of surveillance teams, medical social workers and other health workers in HIV/AIDS counselling. All of these groups were given a five-day basic counselling workshop, followed by six months during which they practised their skills while meeting monthly to discuss cases. After this period they attended a five-day advanced counselling workshop. These health workers are now fully trained and are available to train others in HIV/AIDS counselling in other parts of the country according to the plans and priorities of the National AIDS Programme.

- **blood transfusion services.** For example when pre-donation information and counselling are provided to potential blood donors, counselling facilitates the process of confidential self-deferral and/or deferral of high-risk donors. Those who wish to donate blood primarily for the purpose of knowing their HIV status can be referred to a voluntary counselling and testing site, if it exists (see guidelines for counselling blood donors, listed in Annex 1).
- **clinical and epidemiological research.** If such research includes linked HIV testing, counselling is provided as an ethical obligation and as a care and support service to the study participants. Ongoing counselling also facilitates compliance with the follow-up procedures of the research.
- **local social support organizations.** For example, a client who is no longer able to work may be referred to a local AIDS support organization for emotional support and financial or material assistance.
- **organizations that specialize in meeting specific client needs.** For example, a client who is an injecting drug user may be referred to a methadone programme or to a needle exchange programme. A homosexual client may be referred to a local self-help support and advocacy group of men who have sex with men.
- **religious workers.** For example, an AIDS patient may request help in meeting spiritual needs and be referred to a local religious institution.

Figure 3: The HIV/AIDS continuum of care



To be beneficial, voluntary HIV testing, whether initiated by the client or by the health worker, must be:

- part of a comprehensive counselling programme, in which trained counsellors provide counselling before a decision is made about testing (pre-test counselling), and provide counselling together with other supportive services (such as the provision of condoms and safer injecting equipment, where appropriate) or referral after testing (post-test counselling);
- entirely the choice of the individual;
- confidential or anonymous;
- technically sound in terms of laboratory tests used and the quality of the laboratory practices.

See also the statement on testing and counselling listed in Annex 1.

Monitoring and evaluation of HIV/AIDS counselling services

A monitoring and supervisory procedure should be set up to ensure that counselling services are delivered as planned and that any constraints are addressed promptly. This process also enables the professional supervisors of the service to give support to the providers. Evaluations of the impact of HIV/AIDS counselling should be undertaken in order to determine whether the goals of HIV/AIDS counselling have been met. These goals (see page 12) will usually state the purpose for which HIV/AIDS counselling services have been established.

Evaluations should include consideration of the following aspects of the provision of HIV/AIDS counselling services:

- **relevance** (i.e. whether the services are designed to meet a need that has been clearly defined and whether the provision of HIV/AIDS counselling services is the most appropriate way to meet this need);
- **impact** (i.e. whether the services are meeting the intended aim);
- **efficiency** (i.e. whether the services are provided in a cost-effective and timely manner); and
- **progress** (i.e. whether the provision of services is according to plan).

A review of existing documents in the following policy areas at a national or institutional level may form part of the process of the evaluation of HIV/AIDS counselling services:

- policy statements on HIV/AIDS counselling and related areas;

- procedures used in the institutions that are providing services, for example, for counselling and referral;
- standards for the provision of services;
- criteria for monitoring and/or assessing service provision.

The WHO/GPA document *Guidelines for implementing HIV/AIDS* contains guidance on how to establish, maintain and evaluate HIV/AIDS counselling services, including separate tools for setting and monitoring the standard of counselling, evaluating the supportive impact of counselling and measuring the preventive impact of counselling.

HIV/AIDS counselling for women and children

HIV can infect anyone, men, women or children. However, the relative vulnerability of women, children and adolescents will need special attention when counselling services are being developed.

Whilst many of the basic principles of counselling practice are the same for women as for men, several factors should receive special consideration when women are the recipients of HIV/AIDS counselling services:

- (1) Since many women are living in **unequal power relationships** with either their sexual partners or the male members of their families, it may be necessary for the provider of HIV/AIDS counselling services for women, to devote additional time to help the woman to assess and strengthen her ability to negotiate arrangements that will prevent transmission of HIV. The care-provider may refer the woman to an organization or self-help group, if available.
- (2) Because of their **traditional role as care-givers** rather than receivers of care, many women do not give priority to having their own needs for care met. Counselling of women should therefore include helping them to express their own needs for care.
- (3) In many settings whilst reproductive decisions are often made by men, women tend to shoulder the blame and responsibility when things go wrong. The HIV/AIDS counselling process helps women to redress this imbalance providing information, discussing personal difficulties and offering a forum for their partners to become involved in such decision-making.
- (4) As HIV can be transmitted from mother to child via **breast-feeding**, this issue needs special attention when counselling women who are pregnant or who have delivered recently. The risks of breast-feeding should be weighed against the risks to which the child may be exposed as a result of bottle-feeding. For example, a child whose mother is HIV-positive and who lives in an

environment where there is no clean water, is probably at higher risk of dying from diarrhoea if bottle-fed than of dying from AIDS if breast-fed. The GPA document *Human immunodeficiency virus (HIV) and infant feeding: Essential issues for decision-makers* (see Annex 1) provides policy-makers with guidance on how to develop counselling policies concerning breast-feeding and HIV/AIDS.

- (5) **HIV infection in a child** implies that the mother too is infected, unless the child has other risk factors (e.g. blood transfusion or sexual abuse). The mother needs psychological support to help her face this reality. The child may also face negative reactions from other children and their parents due to stigmatization and irrational fear of casual spread of HIV infection. If the child is old enough to understand, he or she should participate in discussions about issues regarding HIV infection and related episodes of illness and the reaction of other children and the community. The document *Guidelines for the clinical management of HIV infection in children* (see Annex 1) contains a chapter on counselling that covers these issues in detail.

Thus, much more time may need to be allocated for counselling female clients and children than for counselling men.

Counselling of adolescents and young people about HIV/AIDS

An adolescent may him or herself be infected with HIV or affected by HIV because a parent, sibling or other family member, a sexual partner or close friend is infected. The counselling of adolescents and young people presents particular challenges:

- (1) The main challenge is that of **balancing the need for confidentiality with the need to meet legal responsibilities towards the young person's family**. For example, a young person who has a tumultuous relationship with his or her parents may not be willing to use services that may inform the parents of drug problems or a history of STDs. This may mean that young clients who could be helped if they were to come forward for counselling may instead retreat from it.
- (2) There is a marked tendency to **label the adolescent client who has a problem**. For example, many agencies automatically conclude that the young client with drug problems is also the one with STDs or the one who is likely to become pregnant. This labelling adversely affects young clients so that they gradually lose their self-esteem and their ability to make sound decisions.
- (3) There is a need for care-providers to fully comprehend the **culture of young people**. Without this understanding, it is very unlikely that a dialogue, which

is the essential feature of effective counselling, will take place between the care-provider and the client.

- (4) **Haemophilia** will present special problems. Mothers may feel guilty because they have not only passed on the haemophilia but, in many cases, have unknowingly injected a contaminated product. When the haemophiliac adolescent has been infected as a young child, the parents have to decide how, when and who will inform the child of this fact. Parents often postpone this until puberty when they say, "sex may come onto the scene". Box 6 illustrates some issues which may arise during a counselling session with an HIV-infected haemophiliac adolescent.

Youth counselling services, where they are available, often have many years of experience in meeting the particular needs of young people and may provide an appropriate location for HIV/AIDS counselling services for adolescents and young people. See the document *Counselling skills training in adolescent sexuality and reproductive health*, listed in Annex 1.

Box 5. Counselling of an HIV-positive adolescent with haemophilia

A family interview with parents and a boy of 15 with haemophilia and HIV infection is used to illustrate how concerns are identified and information that might previously have been kept secret is shared with family members. This is a follow-up counselling session; the boy has already received post-test counselling and he knows he is HIV-positive. His 13-year-old brother is at school and has not been brought to the interview.

- Counsellor: Mr J., what have you told Peter about why we are here today?
Mr J.: I said we were coming for a check-up and to discuss anything that is worrying us.
Counsellor: Is this what you understood, Peter?
Peter: Yeh.
Counsellor: Mrs J., your husband said you had all come to discuss your worries. Is there anything that you think is worrying your husband?
Mrs J.: Yes, there is. It is what effect it will have on Peter knowing now that he has HIV. We are worried sick.
Counsellor: What most worries you, Mrs J.?
Mrs J.: That he won't be able to marry and have children.
Counsellor: Peter, did you know that Mum was worried about this?
Peter: Not really.
Counsellor: Do you worry about not having children?
Peter: Not really.

- Counsellor: Peter, I wonder who you think might worry most about this, you, your father, mother, your grandparents or your brother?
- Peter: I don't worry about it. My mother does and so does granny. She only wants me and my brother to have kids.
- Counsellor: So, Peter, you think that your granny puts pressure on your mother?
- Peter: She is always worrying about those things.
- Counsellor: Mrs J., did you know that Peter thinks you and your mother are most worried about this and Peter least?
- Mrs J.: I didn't realize that was how he saw it.
- Counsellor: Mr J., what is your greatest worry today?
- Mr J.: That Peter won't work at school because he won't see the point.
- Counsellor: What do you think about what Dad has said?
- Peter: He just worries that we get a good job. I find work boring at school.
- Counsellor: What would you prefer to be doing?
- Peter: I don't know. There isn't any point, is there, if I'm going to die. You die of AIDS, don't you?
- Counsellor: Yes, you can die of AIDS. Is dying something that worries you?
- Peter: I don't worry about dying. I won't know about anything then. I just want to do what I want.
- Counsellor: What do you want Peter?
- Peter: Not to be nagged all day.
- Counsellor: Just say, Peter, that you keep as well as you are for a good number of years. How would you fill your time?
- Peter: I could get a job.
- Counsellor: Mr J., what is your view about what Peter has been saying? Do any of us know exactly how much time we have got? We could have an accident tomorrow. Do you think that you could discuss with Peter how he might do what he wants, but also show him how difficult it is to get jobs without any qualification?
- Mrs J., we have heard from Peter that he is not worried about dying. Nor is he worried that he might not marry and have children. He gave me the idea that there are many people who can't have children. Some never find partners, some have other illnesses, and others are infertile. So, although this is your worry now, Peter's worries seem different.

Source: Robert Bor, Riva Miller and Eleanor Goldman, *Theory and Practice of HIV Counselling: A Systematic Approach*, London, Cassel, 1992.

HIV counselling and testing

In order to offer national AIDS programmes guidance on the role of HIV testing, a consultation was held in Geneva in November 1992 (see the statement listed in Annex 1). Its purpose was to review what is known about the advantages and disadvantages of HIV testing, and to develop recommendations on the role of testing and counselling in HIV/AIDS prevention and care programmes. The consultation stressed that testing programmes which do not require and secure an individual's informed consent could damage efforts to prevent HIV transmission and are therefore not in the interests of public health. Voluntary testing and counselling can, however, be useful to initiate care and support of seropositive individuals, provide reassurance and support to seronegative individuals, and relieve anxiety in both groups.

How might future developments in AIDS prevention, testing and care affect the demand for and delivery of HIV/AIDS counselling services?

The following future developments in the area of AIDS prevention, testing and care are likely:

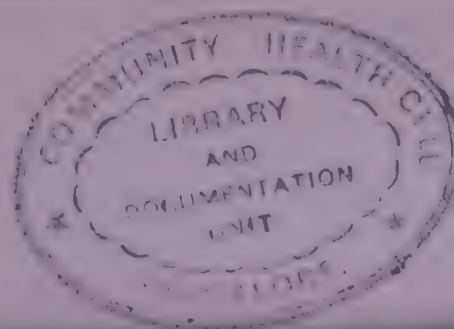
1. The introduction of **rapid HIV tests** in which clients can be informed of their test results within a few minutes will mean that clients may be informed of the results of positive HIV tests before they are emotionally and psychologically prepared to absorb the news. This may lead to additional demands being placed on care-providers. Policies will therefore be needed to ensure that all clients receive adequate pre-test counselling before they are informed of the result of any HIV test.
2. **Self-administered HIV tests**, which could be purchased from pharmacies, could be a popular product in countries where levels of discrimination and stigmatization are highest; for example, in some countries, known HIV-positive status can mean rejection of insurance coverage or loss of job. In such settings, individuals may wish to avoid any possibility of their HIV status becoming public knowledge by purchasing and self-administering HIV tests. Prior to such tests coming on the market, national policies should be put in place to ensure that reference to the need for, and availability of, HIV/AIDS counselling is contained in the instructions and advertisements for such products.
3. **Likely developments in the clinical management of AIDS patients**, leading to prolongation of life beyond what is now the norm, could provide a new rationale for requesting an HIV test. Such developments could lead to an increased demand for voluntary testing and consequently for HIV/AIDS counselling services.

4. **Large-scale trials of vaccines** against HIV will lead to increased demand for HIV/AIDS counselling services. All research protocols for vaccine trials should ensure provision of counselling services for subjects who are involved in the study; such provision should include funds for the necessary training in HIV/AIDS counselling. In countries where vaccine trials are to be conducted, planners will need to put into place strategies to ensure that the increased demand for care-providers with counselling skills is met.

In summary

HIV/AIDS counselling services:

- are necessary to enable affected and worried individuals and families to cope with the effects of HIV infection and with the stress of receiving HIV testing;
- should relate and be linked to other HIV/AIDS activities;
- are usually delivered by providers who have received in-service training in counselling skills to supplement their basic professional training;
- should be established at all sites where care is provided for people with HIV infection and where linked HIV testing is carried out;
- should be integrated into existing health/social/support/religious services.



PART THREE: THE ROLE OF POLICY-MAKERS AND PLANNERS

What are the essential policies and procedures that should be in place before HIV/AIDS counselling services are established?

The HIV/AIDS counselling process is most effective when the following are in place prior to the establishment of services:

- policy statements regarding the objectives and purpose of HIV/AIDS counselling services in the country or institution, including where and to whom counselling should be delivered; and the strategies that are to be followed to ensure that counselling is available/accessible to the desired target group.
- written procedures within each institution or agency providing HIV/AIDS counselling services that will guarantee that testing is confidential and, if requested, anonymous. If needed, there will be procedures for explaining the differences between these two concepts to all clients;
- policies that clearly state that all HIV testing is to be voluntary and to be based on explicit informed consent;
- written policies on who should provide HIV/AIDS counselling: what their professional background should be and what additional training they will need. The role of volunteers as regards different aspects of counselling (pre- and post-test, follow-up counselling) should also be clearly spelt out.

In situations where the above requirements are not met, policy-makers and planners can inform themselves, through discussion with providers of HIV/AIDS counselling services, of the adverse impact of existing policies or lack of policies. This information can be used to gain support for policies and procedures that are consistent with the guidelines contained in this document.

What steps can be taken to develop appropriate policies for HIV/AIDS counselling?

These guidelines have described HIV/AIDS counselling and have answered a series of critical policy-related questions regarding how such services are established and developed. Policy-makers and planners can play a crucial role in the establishment of high-quality HIV/AIDS counselling services. In many settings, a comprehensive review of policies that affect the HIV/AIDS counselling process, and subsequent development and promulgation of new or revised policies, may be necessary. The implementation of the sequence of steps

listed below represents one approach to solving the problem of non-existent or inappropriate policies:

1. Nomination of a coordinator for HIV/AIDS counselling and collection of relevant background information.
2. Identification and prioritization of issues in HIV/AIDS counselling that require policy development or amendment.
3. Detailed analysis of priority issues and selection of appropriate policies to address the issues.
4. Development of draft policy statements.
5. Presentation to and review of draft policies by senior officials.
6. Finalization and dissemination of policies on HIV/AIDS counselling and related issues.
7. Follow-up and monitoring of the implementation of the developed policies.

Step One: Nomination of a coordinator for HIV/AIDS counselling and collection of relevant background information.

Interested members of national AIDS committees, senior planners, and sometimes politicians, will usually take the lead in promoting the development and dissemination of appropriate policies on HIV/AIDS counselling. It may be necessary, as a preliminary step, to nominate a person among this group who will act as a coordinator or focal point for issues pertaining to HIV/AIDS counselling. A first task of this coordinator will be to draw up a list of all those who should be involved in the policy development process. Examples of individuals who might be included on this list are:

- the National AIDS Programme Manager;
- the focal point for HIV/AIDS care;
- the HIV/AIDS IEC focal point;
- interested members of the National AIDS Committee;
- senior planners in the Ministry of Health;
- representatives from institutions that are providing HIV/AIDS counselling services;
- senior psychotherapists;
- senior clinicians; and
- senior representatives of nongovernmental organizations involved in HIV/AIDS care and prevention.

The coordinator will also be responsible for preparing or commissioning the preparation of a report on the current status of counselling services in the country, region or institution for which policies are to be developed. This report will include:

- up-to-date epidemiological information on HIV/AIDS and a brief discussion of the implications of this information for the policy-makers and planners of HIV/AIDS counselling services;
- an assessment of the existing, and likely future, demand for HIV/AIDS counselling services;
- a description of existing services including:
 - * details of institutions providing services;
 - * details of existing counselling training programmes; and
 - * an assessment of the strengths and weaknesses of existing services.

Annexes to the report will include copies of relevant documents that help to describe the current status of services such as:

- written counselling policies that are already operative;
- written procedures that are already in place in locations where HIV/AIDS counselling is being undertaken;
- current counselling training programmes;
- summaries of any reports or evaluations of services that are available.

Step Two: Identification and prioritization of issues in HIV/AIDS counselling that require policy development or amendment.

Each of the participants in the policy-making process (such as those listed in step one) should be asked to submit a list of priority issues that require policy development or amendment. This is done after they have read these guidelines and have had the opportunity to consult with colleagues and constituents. It may be appropriate to organize a short workshop at which clarification of some of the issues that are discussed in these guidelines, and of issues that are raised by the participants, is undertaken before a final list of critical policy issues is drawn up and agreed. It is to be expected that issues raised during this step will vary greatly from setting to setting depending on the local context. For example, in a setting where HIV prevalence is high, there may be a need for policy development, particularly as regards the question of "who are the counsellors?" In a setting where HIV prevalence is low, but where levels of potential discrimination against HIV-infected persons may be higher, the main issue may relate to the need for firmly-stated policies on issues of confidentiality and partner notification.

The list of issues identified is then circulated to all participants in the policy development process and each participant asked to rank the items on the list in order of importance. The totals are then collated and analysed and the results used for selecting priority policy issues. It is suggested that only the first five or six items on the list should be included in the final list of priority issues.

Step Three: Detailed analysis of priority issues and selection of appropriate policy tools.

Each priority issue should then be examined in detail and statements made about the content of the policies that will be formulated to resolve each issue. The resulting policies may be general or quite specific. An example of a general policy is: "HIV/AIDS counselling services are to be available in all District Hospitals". An example of a very specific policy is: "HIV/AIDS post-test counselling is to be carried out only by nurses or social workers trained in counselling".

Policies may be implemented by various means:

- **legislation** making mandatory testing illegal;
- **a directive** or order informing all health workers of confidentiality provisions in relation to HIV/AIDS;
- **provision of incentives** allowing health or social workers academic credit for attending workshops on HIV/AIDS counselling;
- **preferential treatment** giving non-monetary rewards to HIV/AIDS counsellors who work on a voluntary basis; and
- **indirect incentives** offering exchange visits by HIV/AIDS counsellors to other institutions.

Some policy issues may best be resolved by using a combination of the above tools.

Step Four: Development of draft policy statements.

Written policies covering each of the issues that have been analysed are then drawn up. However, some circumstances, such as possible public opposition to a particular policy, may necessitate a delay in formulating written policies; even under these circumstances implicit policies can be developed and can be incorporated into counselling training and procedures.

Step Five: Presentation to and review of draft policies by senior officials.

The draft policy statements are then presented to the senior officials under whose "imprimatur" the policies will be disseminated. The policies are reviewed by these officials and are either approved or returned for further development or modification.

Step Six: Finalization and dissemination of policies on HIV/AIDS counselling and related issues.

After review and approval, the new policies are widely disseminated. Any retraining of HIV/AIDS counsellors that may be necessary to bring their practice into line with the new policies is undertaken at this time. Furthermore, an effort should be made to sensitize managers and staff of sites where counselling is to take place about the status of counselling. HIV/AIDS counselling, being a relatively new domain, is often regarded with suspicion and uncertainty. The role of counselling in HIV testing and in the care of patients will need to be discussed at every counselling site. These discussions, and perhaps seminars, form part of the process of dissemination of policies on HIV/AIDS counselling.

At this time the senior officials may be encouraged to solicit personal testimonials from political figures or other well-known individuals. The positive impact of such testimonials to back up a proposed change in policy, particularly one which aims at reducing the stigmatization to which HIV-positive persons are exposed, has been demonstrated in several countries when very senior politicians have come forward with personal statements about the impact of HIV/AIDS on their family or community.

Step Seven: Follow-up and monitoring of the implementation of the developed policies.

Once the policies are disseminated, a mechanism to ensure their implementation is needed. This monitoring process will also be useful in determining which policies need revision and how they can be revised.

Box 6 shows an example of an executive summary of national counselling policy statements.

Technical materials and guidelines for HIV/AIDS counselling and related areas.

In order to implement these policies, programme managers will need to develop more detailed technical guidelines on HIV/AIDS counselling, including how to develop and evaluate services and how to train counsellors. In addition, guidance is needed on how counselling interacts with other aspects of HIV/AIDS care, prevention and research.

WHO/GPA has prepared a series of materials (see Annex 1) giving guidance on specific issues such as:

- how to establish HIV/AIDS counselling services;
- how to train HIV/AIDS counsellors;
- how to incorporate an HIV/AIDS counselling component into blood transfusion services;
- how to advise HIV-positive mothers regarding breast-feeding.

In summary:

- It is essential to develop policies related to HIV/AIDS counselling in order to allow smooth introduction of HIV/AIDS counselling and its acceptance by health professionals.
- Policy-makers should consult widely before prioritizing the policies to be developed.
- Relevant material should be developed to facilitate training and service development in order to implement the policies.

Box 6. An example of a policy statement on counselling: Kenya

It is the Ministry of Health Policy that:

- All health workers should be trained to provide counselling services on a continuous basis.
- Counselling should not be focused on patients alone, but be extended to the family.
- There should be district plans of action for AIDS counselling.
- Confidentiality and ethics should be adhered to at all levels of activities.
- The rights of the individual, culture, social fabrics, etc. should be taken into consideration in AIDS counselling.
- Confirmation of HIV infection or AIDS in an employee provides no grounds for refusal of employment or dismissal.

Source: Kenya, Ministry of Health, *National guidelines on counselling for HIV infection*, December 1988.

Annex 1

WHO/GPA Materials on Counselling and Related Areas

Testing

Statement from the Consultation on Testing and Counselling for HIV Infection, Geneva, 16-18 November 1992 (document WHO/GPA/INF/93.2).

Guidelines for counselling blood donors on HIV (document WHO/GPA/TCO/HCS/94.2)

Training

HIV prevention and care: Teaching modules for nurses and midwives (document WHO/GPA/CNP/TMD/93.3).

Human immunodeficiency virus (HIV) and infant feeding: Essential issues for decision-makers (in preparation).

Living with AIDS in the community (document WHO/GPA/IDS/HCS/92.1 Rev.1).

Source book for HIV/AIDS counselling training (in preparation).

An orientation to HIV/AIDS counselling: A guide for trainers (WHO Regional Office for South-East Asia, New Delhi).

Clinical management and care

Guidelines for the clinical management of HIV infection in adults (document WHO/GPA/IDS/HCS/91.6)

Guidelines for the clinical management of HIV infection in children (document WHO/GPA/IDS/HCS/93.3).

AIDS home care handbook (document WHO/GPA/IDS/HCS/93.2).

Counselling service delivery

Counselling skills training in adolescent sexuality and reproductive health (document WHO/ADH/93.3)

Guidelines for implementing HIV/AIDS counselling (in preparation).

NAP Programme Management Training Course: Module on HIV/AIDS care and social support (1993).

Annex 2

Glossary

Client: The person seeking or receiving HIV counselling and/or testing. In the case of a child or other person unable to consent to testing on his/her own behalf, the client is the parent or other adult with the ethical and legal competence to do so.

Counselling: A confidential dialogue between a client and a care provider aimed at enabling the client to cope with stress and take personal decisions related to HIV/AIDS. The counselling process includes an evaluation of personal risk of HIV transmission and facilitation of preventive behaviour.

Pre-test counselling: Dialogue between a client and a care provider aimed at discussing the HIV test and the possible implications of knowing one's HIV serostatus, which leads to an informed decision to take or not take the test.

Post-test counselling: Dialogue between a client and a care provider aimed at discussing the HIV test result and providing appropriate information, support and referral, and at encouraging risk-reduction behaviours.

Testing:

- 1) Laboratory testing, i.e. application of an assay (e.g. ELISA) for laboratory markers of HIV infection such as HIV antigen or antibodies. The assay may be used in order to screen blood for transfusion, or organs or tissue for transplantation (see **screening**), or in order to test an individual (see **testing 2**)).
- 2) More broadly, the testing of individuals with the intention to determine their HIV infection status. All testing in this sense can be categorized according to three sets of criteria:
 - a) client-initiated, health care provider-initiated, or initiated or required by a third party for other than health purposes;
 - b) with or without informed consent; and
 - c) anonymous, confidential, or non-confidential. These terms are defined below.

Client-initiated testing: HIV testing requested by a client on his/her own initiative.

Health care provider-initiated testing: HIV testing initiated by the client's health care worker.

Testing initiated or required by a third party for other than health purposes: HIV testing for other purposes, such as immigration, employment or insurance.

Testing with informed consent: HIV testing performed only after the client has given informed consent to it. **Informed** in this context means that in discussion (pre-test counselling) the client has been made aware of all the ramifications of HIV testing, including the risks and benefits, as well as of alternatives to such testing, in language he/she can understand. **Consent** means the giving of express agreement to HIV testing in a situation devoid of coercion, in which the client should feel equally free to grant or withhold consent.

Testing without informed consent: HIV testing in which informed consent, as defined above, has not been requested and given.*

Voluntary testing: Anonymous or confidential testing initiated by either the client or his/her health care provider and performed with the client's informed consent.

Mandatory testing: HIV testing without informed consent which the individual is compelled to undergo. The term refers both to situations in which the individual clearly has no alternative - as when prisoners are tested involuntarily - and to situations in which refusal of testing is not realistic or would cause the individual undue hardship, as when HIV testing is required prior to employment or marriage.

Anonymous testing: HIV testing in which the blood sample and test result are identified only by code, not by name, with no personal identifiers to link the sample to the donor source.

Linked anonymous testing: HIV testing in which the code is known only to the client.

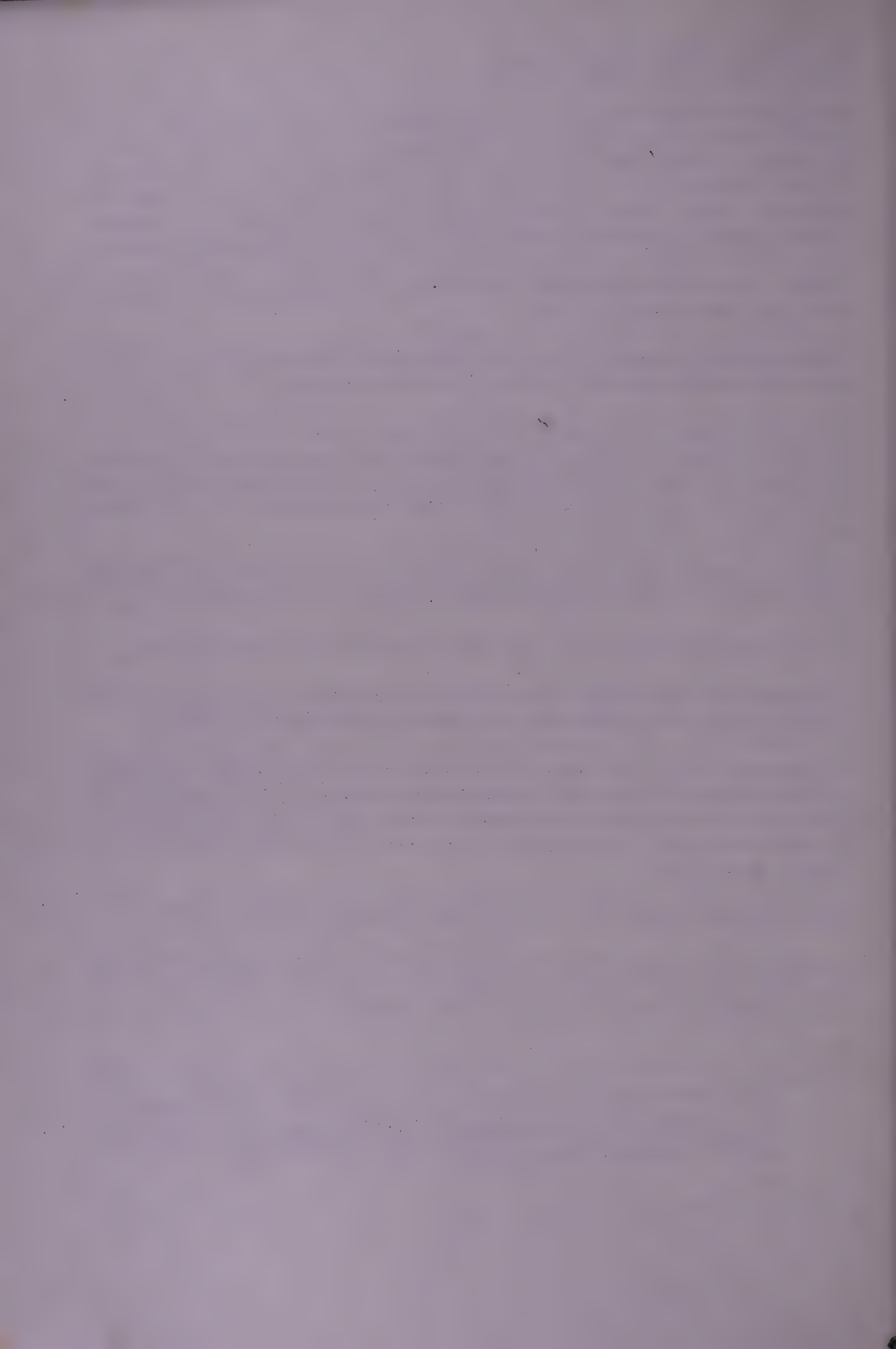
Unlinked anonymous testing: HIV testing (e.g. for surveillance purposes) after prior removal of all personal identifiers, so that retrospective identification is impossible.

Confidential testing: HIV testing in which only the client and the health professionals involved in the client's direct care know that the test was performed and have access to the test results. This information is not furnished under any circumstances to other health care providers, health authorities, employers, insurers, schools or other third parties without the patient's explicit consent.

Non-confidential testing: HIV testing conducted neither anonymously nor confidentially.

Screening: The systematic laboratory testing of donated blood, blood products, tissue (including sperm) and organs for the purpose of preventing HIV transmission to the recipients. Other specimens, such as saliva, may also be used.

* The term "Routine testing" is sometimes used to mean the HIV testing of individuals without their knowledge or unless they specifically refuse such testing. Examples are routine testing policies applied by hospitals to patients, and sometimes applied to people attending antenatal or STD clinics. This term should not be used because it does not specify whether informed consent is requested and granted.



4

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



EDITORIAL REVIEW

Enabling approaches for HIV/AIDS prevention: can we modify the environment and minimize the risk?

Oussama Tawil, Annette Verster* and Kevin R. O'Reilly

AIDS 1995, 9:1299-1306

Keywords: AIDS prevention, risk behaviour, determinants of risk, enabling, environmental factors, structural interventions

Introduction

The search for effective intervention approaches to reduce the spread of HIV/AIDS is an ongoing one. Although the international AIDS research community has accumulated considerable experience with interventions and has made realistic assessments of their effectiveness [1,2], it continues to debate the relative importance of different approaches, including, for example, which channels of communication or which risk-reduction messages should be promoted. While such debate remains necessary, it can also distract us from thinking more broadly about HIV prevention. The need for multi-faceted intervention approaches has already been well established [3], but so also has the need for broader thinking about prevention options [2,4,5]. In this review, we examine one area that has received insufficient attention in HIV prevention: influencing the social and environmental determinants of risk, or what we call 'enabling' approaches.

Background

Influenced by such disciplines as social and clinical psychology, and guided by a public-health tradition with a strong emphasis on clinic-based interventions, most HIV prevention efforts continue to focus on changing behaviour of individuals. Such efforts usually involve increasing personal awareness and risk perception, raising expectations of favourable outcomes of risk avoidance, teaching the necessary skills to undertake behaviour change, fostering the perception of personal capability to undertake change and of the social acceptance of risk avoidance. The premise underlying this ap-

proach is that individuals will take appropriate decisions about personal behaviour and, subsequently, will act on those decisions. A number of theories have described the cognitive mechanisms involved in this process relative to preventive health behaviour [6-8], and their practical application has yielded results in various health domains [9-11]. However, these theories may have limited utility when considering social and environmental determinants of HIV transmission [12-14]. These determinants go beyond individual volition [15] and must be addressed in addition to influencing personal decisions about behaviour. Rethinking prevention approaches is therefore necessary to develop a wider range of options in an effort to complement existing strategies.

A distinction is made here between prevention approaches that aim to 'persuade' individuals to undertake behaviour change and those that 'enable' change to occur. The latter focus on the non-individual, or the social and environmental, determinants that facilitate or impede behavioural choice. Enabling approaches intend to remove barriers or constraints to protective action or, conversely, to erect barriers or constraints to risk-taking. In some cases, enabling approaches that remove barriers for some people, such as for women who may have little say in sexual matters, may actually erect barriers for others, such as for men who may find their traditional dominance constrained. An enabling approach that removes a barrier to change might be a policy that allows the purchase and possession of sterile injection equipment by drug users, while an example of an enabling approach that erects a barrier to continued risk taking might be a policy mandating condom use in commercial sex establishments.

Recent evidence has shown that altering the environment in which risk behaviour takes place through com-

From the Global Programme on AIDS, World Health Organization, Geneva, Switzerland and the *AIDS Coordination Municipal Health Service, Department of Public Health and Environment, Amsterdam, The Netherlands.
Requests for reprints to: Dr Kevin O'Reilly, Global Programme on AIDS, World Health Organization, CH-1211 Geneva 27, Switzerland.

prehensive sexually transmitted disease (STD) treatment can result in decreased HIV incidence even in the absence of any significant behaviour change [16]. This is further evidence of the preventive effect of a structural intervention, albeit a physical one which relies on enhanced service delivery. While continuing to recognize the role of individual decision-making, all structural interventions acknowledge that meaningful reduction of HIV transmission can still occur even though the range of an individual's action may be too limited in certain contexts to allow for sufficient behaviour change.

Focusing on social and environmental determinants is not so much an innovative approach as it is a confirmation of recommendations already espoused by the World Health Organization and other health agencies. The principles guiding disease prevention and health promotion were developed in the 1986 Ottawa Charter [17]. Five steps were identified in the charter: apart from the necessity of developing skills, attention is also focused on introducing appropriate health legislation, creating supportive environments, strengthening community-based action and reorienting health services. These steps place health within a broader social agenda. They also place attempts to motivate individual action in the wider context of attempts to modify conditions of risk-taking [18,19]

The term 'enabling' is not new to public health. Enabling factors have been described previously to refer to those factors that make a desired change in behaviour possible [20], so that planning for a health education programme should include motivating people to action and also removing barriers that people might encounter. Others have suggested that, to be successful, health education must include an initial focus on the policy and normative environment in which a programme will develop, as a supportive environment can facilitate, and a hostile environment impede, effectiveness [21,22]. In the context of AIDS, enabling has been used to refer to the vulnerability of populations, for example, the obstacles that women encounter in reducing risk of HIV and the corresponding need to address these obstacles [23].

Although health behaviour theory does recognize the influence of social and environmental factors on individual behaviour [24,25], this recognition is rarely carried into intervention strategies [26-28]. One source of difficulty is that non-individual risk factors are essentially of a structural nature and, therefore, not perceived to be easily modifiable [28-30]. Another possible explanation is that HIV transmission relates to sex and drug use, both areas generally subject to taboo. The relationship between such behaviours and social and environmental factors has also never been well understood and is not easily explored. In addition, the discourse of decision-makers in AIDS is largely a biomedical one [27,31] to which only the more 'scientific' models and evaluation designs, more easily measuring change in individuals than in communities, appear credible. Thus, community and societal-level changes, being difficult to quantify and measure, are relegated to the realm of the non-scientific.

In our discussion of enabling approaches, we specifically exclude attempts to alter prevailing social norms about risk behaviours and HIV prevention. While these approaches are in themselves very important, they are somewhat different from the present concern. Their effect on behaviour is through individuals' perceptions, and the choices individuals make about behaviour. Social norms also have a role in shaping the national discourse about prevention and are therefore important in creating a supportive environment in which prevention can take place. Nevertheless, in this review, we limit our concerns to those structural interventions which directly remove barriers to behaviour change or erect barriers to persistent risk-taking. Two categories of determinants, and hence two types of enabling approaches, are examined in this review: economic and policy. The assignment of a specific factor to either of the two categories, however, can be somewhat arbitrary given that they are interrelated.

Economic constraints and behaviour change

Health research has shown that populations of lower socioeconomic status are also those at higher risk of morbidity and mortality resulting from health-related problems [19]. Poverty has been associated with increased risk for a wide variety of both infectious and chronic diseases, and also with limited access to health care [29]. This finding equally applies to AIDS, as the disease has, in recent years, come to affect disproportionately poorer communities [30,32,33]. Thus, not only are poorer rural and urban communities least able to bear the economic consequences of AIDS once the epidemic is established, they are initially at heightened risk of infection. Recognition of links like these between poverty and bad health outcomes is one of the factors that drives development programmes worldwide.

Even for those who are not poor, however, an economic dimension to risk behaviours may exist. In the history of public health, numerous attempts have been made to limit or discourage risky behaviour or, conversely, to encourage healthier behaviours through the use of economic incentives. Favourable insurance rates for automobile drivers with safe driving records or for individuals who do not smoke, drink immoderately, or who exercise regularly are economic incentives used by insurance companies to reinforce certain low-risk behaviours. Elevated prices on harmful products have also been tried, as in the case of taxation on liquor in many countries or, more specifically, on tobacco products in Canada. Evidence from that country indicates that, for some groups like adolescents, smoking may be a price sensitive behaviour that can be decreased through increased taxation (Fig. 1) [34]. Similar experience has been reported from Brazil, where the elimination of a tax on imported condoms greatly reduced the price to

consumers and is believed to have contributed to a substantial increase in condom sales (L. Rodrigues, personal communication, 1995). Affordable pricing is one of the elements of social marketing programmes for condoms and other commodities as well.

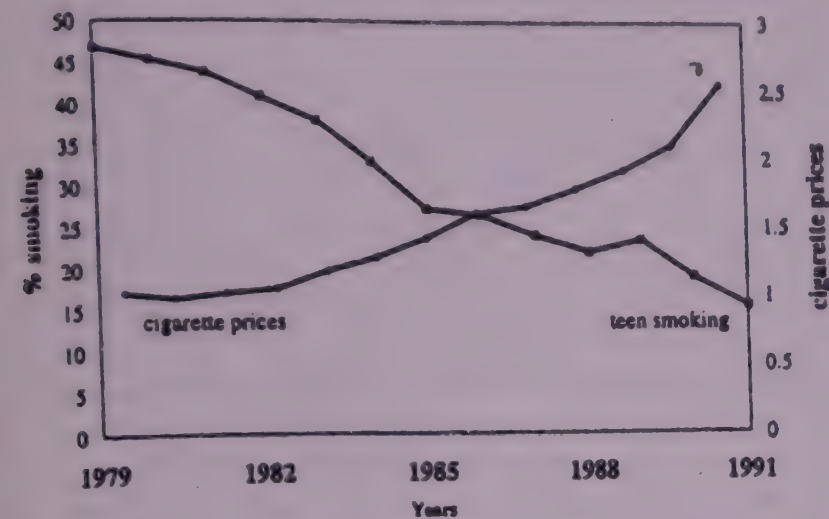


Fig. 1. Effect of cigarette prices on smoking among Canadian teenagers, 1979–1991 [34].

In recent years, AIDS research has increasingly focused attention on the vulnerability of women in sexual relationships [30,35,36], particularly when considering the constraints on women to propose or negotiate risk reduction practices with their partners [37,38]. One explanation advanced is prevailing social norms on gender roles, which encourage men but not women to make decisions about sexual matters [38]. Yet this vulnerability may also be a result of economic factors, such as women's limited access to resources and their subsequent financial dependence on their partners.

Economic factors, such as the need for some to leave their families, seek shelter in new settings, and live apart from regular partners for extended periods, heighten the probability of casual sex and the risk of HIV transmission among men and women alike. Seasonal migrant workers, truck drivers and soldiers are some of the predominantly male occupational categories associated with increased risk of HIV [39,40].

Patterns of drug use may also be associated with economic factors. Although drug use is commonly viewed as a consequence of psychopathology and influenced by peer norms, the conditions that affect initiation, mode of administration and access to treatment facilities may be shaped by economic considerations [18,33]. For example, injecting drug use can become more common than other modes of administration when it is perceived to be a less expensive way to get 'high' [41].

In no case is the evidence for the economic determinants of risk behaviour clearer than it is for sex work. Evidence from all regions of the world suggest that the overwhelming motive behind the exchange of sexual services for the provider is economic opportunity [33,42,43]. Whereas this is often a desperate survival strategy for some, it can sometimes be a lucrative alternative to exist-

ing employment opportunities for others [44]. In Thailand, for example, some female sex workers are able to generate incomes 25 times greater than textile workers [43]. In one case in Northern Thailand, the existence of training programmes and subsequent employment in the textile industry, at substantially lower wage, are not sufficient by themselves to stem the flow of young women into sex work; programme staff must also persuade family members that sex work is less acceptable employment for young girls in the age of AIDS than it once was [45]. The absence of employment opportunities to generate incomes of comparable magnitude or of educational opportunities that might lead to such employment, is why some may chose to remain in sex work [33,43].

Those involved in exchanging sex for money often have limited power to negotiate safer sex practices with clients [46]. Some of the more immediate factors explaining this include: (1) price of sexual encounter (those who earn less usually need more clients, limiting their ability to refuse services and exposing them to greater risk); (2) price of condoms (the price of condoms relative to earnings can influence the frequency of use); (3) earnings provided to third parties (many of those involved in sex work have to pay brokers, brothel or bar owners, and, in some cases, their regular partners a proportion of their earnings); (4) access to other sources of income (the absence of an alternative source of income could determine the number of clients which, in turn, influences the negotiating capacity) [42].

What are the possibilities of modifying economic determinants to reduce the risk of HIV? For sex work, a range of approaches has been proposed in the literature [28], of which relatively few have been attempted and even fewer have been evaluated. Most aim to reduce risk-taking by alleviating economic pressures on those entering or already involved in sex work [45]. A distinction can be made between approaches designed to intervene within the sex work context and those that intervene to prevent or reduce dependency on sex work (Table 1). All the options in the first column necessitate collective action to alter work conditions. This is possible when 'gatekeepers' at sites, such as bar owners and leading figures among sex workers, support such efforts. Examples of such collective action exist from Nigeria [47], Mexico [48] and Zimbabwe [49], all of which have demonstrated increased condom use. The options presented in the second column apply to all groups who are economically vulnerable to HIV infection. Approaches to increase the economic role and power of women as a means of increasing their ability to exercise control over their lives, including over their reproductive and sexual behaviour, have been tried in a number of places. Examples of such approaches exist from India [50], Zambia [51] and Bangladesh [52]. In Zambia, women fish traders are frequently forced to provide sex in addition to cash to obtain fish from fishermen. These women are now being encouraged to participate in economic cooperatives that conduct collective bargaining for fish, as a way to protect

themselves from sexual exploitation [51]. In Bangladesh, rural women participating in a revolving loan scheme have been found to be economically empowered and to exercise greater control over their sexual behaviour as shown by their elevated rate of contraception use (Table 2) [52]. Although requiring a community interest and collective bargaining effort, such measures may initially involve considerable input from external sources.

Table 1. Examples of economic approaches to HIV prevention in sex-work settings.

Interventions
Within sex-work settings
Enforce condom use in all client contacts
Integrate the cost of condoms into the price of sexual encounter (or in the rent paid by clients for rooms)
Raise prices for sexual encounter
In communities where sex work exists
Improve young women's level of literacy and education
Identify alternative income sources or provide vocational training
Develop money management and savings skills
Establish economic cooperatives
Facilitate access to accommodation

Table 2. The effect of women's empowerment on contraception use, Grameen Bank, Bangladesh, 1992 [52].

Economic and social influences on contraceptive use	% of married women aged < 50 years using contraceptives
Empowered*	65
Not empowered	45
Contributes substantially to family support	60
Contributes little or nothing	44
Living in Grameen Bank villages	54
Living in comparison villages	43

*Defined according to the following measures: mobility and visibility, economic security, status and decision-making power in the household, ability to interact in public spheres, and participation in non-family groups.

However, even in those societies where they clearly have a central economic role, women may continue to have limited negotiation power in sexual decision-making. Culturally propagated conceptions of gender roles defining men as the decision-makers often override other considerations and will continue to offer a barrier to significant HIV risk reduction for women [30,53]. Economic approaches such as those outlined above should be considered in conjunction with approaches that attempt to alter prevailing social norms. Whereas the examples here have primarily focused on women, HIV prevention for both sexes could benefit from such economic enabling approaches.

National policy, local practices and HIV prevention

As stated previously, standard health promotion practice has long recognized the importance for a supportive policy environment in which a prevention agenda can be pursued. National policies that recognize and condone the desirable outcome of disease prevention and health promotion are indeed an important first step. Throughout the history of public health, however, policy has also been directly employed to promote health. Policies mandating preventive actions such as childhood immunizations, seat belt use, motorcycle helmet laws, and fluoridation of water are examples of one type of approach. Proscriptive policies prohibiting specific health-threatening actions such as the sale of alcohol or tobacco to minors, the use of tobacco products in public settings or the sale of controlled substances for non-medical purposes, are examples of another use of structural interventions in the pursuit of public health. Similar applications for HIV prevention are much rarer but do exist. In this section, we examine the need for, and the use of, policy for HIV prevention, both as regulation at the national level and as consensus at the local level.

Restrictive legislation may act as a barrier to the adoption of preventive measures. Because of this, policy reforms have been advocated, particularly in countries where the urgency to prevent HIV has been recognized. The threat posed by the AIDS epidemic, for example, has led to calls for the decriminalization of prostitution [54] and less repressive laws concerning drug use [55,56]. In many countries, debate continues about legislation to allow distribution of condoms in schools or condoms and needles in prisons. Arguments have been made that such policy changes will facilitate HIV prevention efforts and provide greater access to health and other services.

The difficulties of changing established policy are immense and it is evident that such changes are unlikely to occur in many countries. Furthermore, it may be too simplistic to believe that tolerant legislation always creates the best environment for HIV prevention and intolerant ones the worst [57]. Effective HIV prevention for sex work have been achieved in some countries despite the illegality of prostitution [44]. Even among advocates for groups vulnerable to HIV, consensus does not exist on the appropriate policy reforms; for example, will decriminalization of prostitution ease or enhance exploitation of those involved [54]? Furthermore, some apparently tolerant societies find difficulty in taking actions that may impinge on individual rights and choices. This is especially true when the HIV prevention agenda has become intertwined with broader social agenda and issues of individuals' rights. For a long time, cities like San Francisco and Amsterdam debated closing gay bath houses, as does Toronto now. On one hand, it was argued that such an action would reduce possibilities

of unprotected multiple partner sex. Opponents argued, however, that bath houses offered a good opportunity for HIV prevention and that closing them would simply drive the behaviour underground, away from the reach of public health [58]. Similar actions have been more easily taken in other public-health domains, where the perceived benefit for the common good has been believed to supersede the potential limitations to the rights of individuals. Although none dealt with such a personal issue as sexual behaviour, the addition of fluoride to water, the requirement that passengers in cars wear seat belts and the proscription on smoking in public places are all public-health regulations that engendered controversy when they were first introduced but are now accepted.

Policies and their enforcement can vary between communities [18]. Unlike the experience of countries such as The Netherlands where policy on HIV prevention has been fairly liberal, decision makers in most countries remain cautious. Often, national policy has been tailored to the local needs [59]. Harm reduction, for example, has a goal of reducing the negative consequences of drug use, including HIV infection. The provision of clean injecting equipment to drug users, as well as information on how to continue to inject more safely, is one of these controversial approaches that are often pursued at the local level despite prohibitive national policy [60]. Unable to reach national consensus, the introduction of needle-exchange programmes was left to local decision makers.

Accepting the priority of HIV prevention over that of drug-use control is essential in adopting an integrated approach to HIV risk reduction. Evidence has shown that early action to make sterile injection equipment available is one of the key factors in maintaining stable low seroprevalence of HIV among injecting drug users [61]. Examples from several countries demonstrate the possibility of adopting such an integrated policy, where public health and law enforcement work together flexibly to meet both the needs of drug control and HIV prevention [62]. An experiment in tolerant policy on drug use in Zurich is a case in point. Designed at least in part with HIV prevention in mind, the policy created a zone of tolerance for drug use in the centre of the city, bringing the risk behaviour into the open where needle distribution and HIV prevention could be promoted. The policy may have in fact been successful in preventing HIV transmission but it had the unforeseen consequence of attracting large numbers of drug users from other cities and countries [63]. For that reason, the policy has now been discontinued and has been replaced in part by an expansion of an existing medically-supervised prescription heroin experiment [64].

In the area of prostitution, an example of the adoption of national regulation exists. Brothel owners in Thailand have been encouraged to implement the 'condom-only brothel' policy [65]. This policy regulates the behaviour of all clients visiting commercial sex establishments by mandating condom use. This has been one of the fac-

tors believed to be responsible for substantial increases in condom use in commercial sex and substantial decreases in STD seen in recent years (Fig. 2) [66].

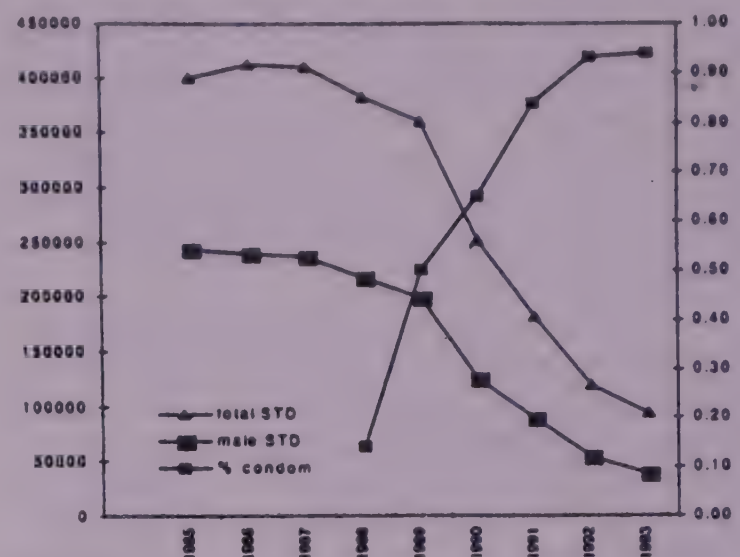


Fig. 2. Reported sexually transmitted disease (STD) cases (total and male) and estimated condom use in commercial sex, Thailand 1985-1993 [66].

Aside from national policy, attempts have also been made in specific communities to modify contexts which encourage risky sexual practices. In many African countries, initiation rites and funeral ceremonies may include multiple partner sex [67-69]. Most efforts to address this have targeted local officials and opinion leaders. Both in Zambia and Uganda, HIV prevention depended on religious leaders and village elders taking action to modify sexual practices associated with funeral ceremonies. Culturally acceptable alternatives to these risky practices were found and promoted [70]. Another approach is the development of alternative social venues for homosexual men, as was tried in American city, offering activities through which it was possible for men to meet without the sexual overtones of the gay bar [71]. Objections by a local politician to the use of government funds for this project led to its early discontinuation. In another example from Hong Kong, a 'safe sex' brothel was established to serve the needs of the local expatriate business community. This brothel, managed by social workers, reputedly provided its services without risk of STD or HIV before questions raised in the local press led to its closure [72]. In Viet Nam, many drug users get their heroin injected by 'community injectors' [41]. As numerous persons are injected with the same equipment, the potential for rapid transmission is clear. However, these same community injectors can also promote safer injecting practices.

Modifications of local practices, such as those listed above, can be promising avenues for HIV prevention. Together with national policy change, these structural interventions are a powerful addition to, not a replacement for, the more standard HIV/AIDS prevention approaches recommended. As we have seen in some of the examples, however, careful preparation and consensus building are necessary to assure the implementation and continuation of these approaches.

Conclusion

To date, AIDS prevention efforts around the world can be characterized as being too little, too late and too narrow. While countries are being exhorted and assisted to move quickly and with intensity on HIV prevention, the range of actions proposed is still narrow. As yet, AIDS prevention efforts have had limited experience with efforts that aim to modify the context of risk-taking or to go beyond debates on how to reinforce prevention efforts. It is, therefore, urgent to broaden the range of prevention options through innovative approaches addressing the context of risk.

How can this be interpreted into practical recommendations? On the broader level, international agencies are pursuing a policy of integrating HIV prevention into development programmes and allocating resources to restructure health services [73]. This is part of a long-term strategy which aims to reduce the potential for HIV transmission as well as to decrease the general health, social and economic burden of the epidemic. On the community level, there are some examples of initiatives undertaken by non-governmental or governmental organizations to support education, occupational training or other activities for those who are potentially vulnerable to HIV. Questions persist on the impact of these efforts on the AIDS epidemic, however. The discrepancy between the rapid pace of the AIDS epidemic and the much slower pace of the fundamental social change and development proposed casts doubt on whether these approaches can be effective quickly enough.

It is evident that no single approach for behaviour change, no matter how carefully or elaborately designed, will fit all individuals or population groups. However, a selection of intervention approaches tailored to specific determinants of risk can be developed [28]. The introduction of enabling approaches in HIV prevention is necessary. In all cases, this will involve lobbying for political support and policy changes. Long-term approaches will be essential to curb the further development of the epidemic [30], but, more immediately, possibilities do exist to promote a more pragmatic approach to addressing the determinants of HIV risk.

Yet challenges exist in pursuing a prevention strategy that includes enabling approaches. First is the challenge of understanding situations where risk occurs. It is essential to focus on the structures that may impede or facilitate risk avoidance, not just the individual determinants of risk behaviours. Second is the challenge of thinking more broadly and creatively about the intervention options that this understanding suggests might be needed. Third is the need to consult more widely than among the traditional providers of HIV prevention. Useful alliances with those outside public health, in particular in the domain of development, can provide new input into intervention strategies. Fourth is the need to consider how enabling approaches can work with, not replace, behavioural interventions that focus

on the individual. The final challenge relates to evaluation, including the need to demonstrate the feasibility of enabling approaches through flexible evaluation designs. Some AIDS researchers argue that existing behavioural interventions have not been adequately evaluated [74,75]. Evaluation is likely to be even more difficult with enabling approaches, as standard evaluation designs might not be particularly useful. A comprehensive description of the situation and understanding of how the intervention works [76], paired with secondary indicators of behaviour change, are essential starting points in the evaluation of enabling approaches.

In practice, numerous intervention programmes have developed strategies involving improved access to condoms or the provision of adequate health services, particularly STD care, which are in themselves enabling of prevention and behaviour change. However, only a few have developed an enabling approach as the principle prevention strategy, despite the considerable evidence on the obstructive or facilitative role of social and environmental determinants. The development of such interventions is likely to require going beyond the realm of health education and intervention development as it has been customarily defined for HIV prevention. As we have shown, such attempts are common in other areas of public health and in keeping with the comprehensive definition of health promotion. The time to think creatively and more broadly about HIV prevention, to focus attention on the context of risk, and to draw on examples from other areas of public health is upon us.

References

1. World Health Organization/Global Programme on AIDS: *Effective Approaches to AIDS Prevention. Report of a Meeting*. Geneva: WHO/GPA; May 1992.
2. Choi K-H, Coates TJ: Prevention of HIV infection. *AIDS* 1994, 8:1371-1389.
3. Cates W, Hinman AR: AIDS and absolutism — the demand for perfection in prevention. *N Engl J Med* 1992, 327:492-494.
4. Scheper-Hughes N: AIDS and the social body. *Soc Sci Med* 1994, 39:991-1003.
5. Smith LL, Lathrop LM: AIDS and human sexuality. *Can J Public Health* 1993, 84 (suppl 1):S14-S18.
6. Rosenstock IM, Stecher VJ, Becker MH: Social learning theory and the health belief model. *Health Educ Q* 1988, 15:175-183.
7. Ajzen I, Fishbein M: *Understanding Attitudes and Predicting Social Behavior*. Englewood Cliffs, New Jersey: Prentice-Hall; 1980.
8. Bandura A: Perceived self-efficacy in the exercise of control over AIDS infection. *Eval Progr Plann* 1990, 13:9-17.
9. Petosa R, Jackson K: Using the health belief model to predict safer sex intentions among adolescents. *Health Educ Q* 1991, 18:463-476.
10. Prochaska JO, DiClemente CC: Stages and processes of self change of smoking: toward an integrative model of change. *J Consult Clin Psychol* 1983, 51:390-395.
11. Janz NK, Becker MH: The health belief model: a decade later. *Health Educ Q* 1984, 11:1-47.
12. Kashima Y, Gallois C, McCamish M: The theory of reasoned action and cooperative behaviour: It takes two to use a condom. *Br J Soc Psychol* 1993, 32:227-239.
13. Moatti J, Beltzer N, Dab W: Les modèles d'analyse des comportements à risque face à l'infection à VIH: une conception trop étroite de la rationalité. *Population* 1993, 48:505-534.

14. Bloor MJ, McKeganey NP, Finlay A, Barnard MA: The inappropriateness of psycho-social models of risk behaviour for un-prostitutes. *AIDS Care* 1992, 4:131-137.
15. Holmes KK: Human ecology and behavior and sexually transmitted bacterial infections. *Proc Natl Acad Sci USA* 1994, 91:2448-2455.
16. Grosskurth H, Mosha F, Todd J, et al.: Impact of improved treatment of sexually transmitted diseases on HIV infection in rural Tanzania: randomized controlled trial. *Lancet* 1995, 346:530-536.
17. World Health Organization: *Ottawa Charter for Health Promotion*. Copenhagen/Geneva: WHO; 1986.
18. Nutbeam D, Blakey V, Pates R: The prevention of HIV infection from injecting drug use — a review of health promotion approaches. *Soc Sci Med* 1991, 33:977-983.
19. Ashton J, Seymour H: *The New Public Health*. Philadelphia: The Open University Press; 1988.
20. Green LW, Kreuter M, Deeds SG, Partridge KB, Barlett E: *Health Education Planning — A Diagnostic Approach*. Palo Alto, California: Mayfield Publishing; 1980.
21. Hubley J: *Understanding Behaviour: An Action Guide to Health Education and Health Promotion*. London: MacMillan; 1993.
22. Hubley J: Understanding behaviour: the key to successful health education. *Tropic Doc* 1988, 18:134-138.
23. Erben R: The special threat to women. *World Health* 1990, Nov-Dec:7-9.
24. Zimmerman R, Vernberg D: Models of preventive health behaviour: comparison, critique and meta-analysis. *Adv Med Sociol* 1994, 4:45-67.
25. Lupton D: Toward the development of critical health communication praxis. *Health Communication* 1994, 6:55-67.
26. Bassett M: Women in Zimbabwe: a case study. Presented at WHO/GPA Meeting on Enabling Approaches in HIV/AIDS Prevention. Geneva, September 1993.
27. Zwi AB, Cabral AJR: Identifying 'high risk situations' for preventing AIDS. *BMJ* 1991, 303:1527-1529.
28. de Zalduondo B: Intervention research needs for AIDS prevention among commercial sex workers and their clients. In *AIDS and Women's Reproductive Health*. Edited by Chen L, Sepulveda J, Segal SJ. New York: Plenum Press; 1991.
29. Nathanson C: Disease prevention and social change: strategies to reduce adult mortality in developing countries. Presented at Expert Meeting on Behavioral and Social Factors in Disease Prevention, Committee on Population, National Academy of Sciences. Washington, DC, June 1993.
30. Ulin PR: African women and AIDS: negotiating behavioral change. *Soc Sci Med* 1992, 34:63-73.
31. Seidel G: The competing discourses of HIV/AIDS in sub-Saharan Africa: discourses of rights and empowerment vs discourses of control and exclusion. *Soc Sci Med* 1993, 36:175-194.
32. Bloom DE, Glied S: Who is bearing the cost of the AIDS epidemic in Asia? In *Economic Implications of AIDS in Asia*. Edited by Bloom DE, Lyons JV. New Delhi: UNDP; 1993:161-181.
33. Thant M: The economic implications of AIDS in southeast Asia: equity considerations. In *Economic Implications of AIDS in Asia*. Edited by Bloom DE, Lyons JV. New Delhi: UNDP; 1993:135-139.
34. Sweanor D: Tobacco use: the role of pricing. Presented at Expert Meeting on Behavioral and Social Factors in Disease Prevention, Committee on Population, National Academy of Sciences. Washington, DC, June 1993.
35. Schoepf BG: Women at risk: case studies from Zaire. In *The Time of AIDS: Social Analysis, Theory and Method*. Edited by Herdt G, Lindenbaum S. Beverly Hills: Sage; 1992:259-286.
36. Bassett MT, Mhloyi M: Women and AIDS in Zimbabwe: the making of an epidemic. *Int J Health Serv* 1991, 21:143-156.
37. Mane P, Rao Gupta G, Weiss E: Effective communication between partners: AIDS and risk reduction for women. *AIDS* 1994, 8 (suppl 1):S325-S331.
38. Schneider BE: Women and AIDS: an international perspective. *Futures* 1989, 21:72-90.
39. Orton L: Special survey: Tamil Nadu and Madras. *AIDS Analysis Asia* 1995, 1:3-11.
40. Wilson D, Sibanda A, Nyathi B, Lamson N, Sibanda T: Ethnographic and quantitative research to design a community intervention among long-distance truck drivers in Zimbabwe. In *Focusing Interventions Among Vulnerable Groups for HIV Infection: Experiences from Eastern and Southern Africa*. Nairobi: NARESA Monograph; 1994; 2:99-118.
41. United Nations International Drug Control Programme: *Rapid Assessment of the Drug Injecting Situation in Hanoi and Ho Chi Minh City, Viet Nam*. Vienna: UNDCP; 1993.
42. Anarfi J: Sexual networking in selected communities in Ghana and the sexual behaviour of Ghanaian female migrants in Abidjan, Cote d'Ivoire. In *Sexual Behaviour and Networking: Anthropological and Socio-cultural Studies on the Transmission of HIV*. Edited by Dyson T, Lihge: International Union for the Scientific Study of Population; 1992:233-247.
43. Ford N, Koetsawang S: The socio-cultural context of transmission of HIV in Thailand. *Soc Sci Med* 1991, 33:405-414.
44. Boonchalaksi W, Guest P: *Prostitution in Thailand*. Mahidol: Mahidol University; 1994.
45. Kanthanachitra C: Income generation and reduction of women entering sex work in Thailand. Presented at WHO/GPA Meeting on Effective Approaches for the Prevention of HIV/AIDS in Women. Geneva, February 1995.
46. Worth D: Sexual decision-making and AIDS: why condom promotion among vulnerable women is likely to fail. *Stud Fam Plann* 1989, 20:297-307.
47. Williams E, Lamson N, Efem S, Weir S, Lamptey P: Implementation of an AIDS prevention program among prostitutes in the Cross River State of Nigeria [letter]. *AIDS* 1992, 6:229-230.
48. Izazola JA, Valdespino JL, Sepalvada J: Indicators of behaviour modification due to the campaign of prevention of AIDS in Mexico. IV International Conference on AIDS. Stockholm, June 1988 [abstract 9551].
49. Wilson D, Sibanda B, Mboyi L, Msimanga S, Dube G: A pilot study for an HIV prevention programme among commercial sex workers in Bulawayo, Zimbabwe. *Soc Sci Med* 1990, 31:609-618.
50. Gadgil A, Patkar PP: Peer group education among prostitutes of Kamthipura and Khetwadi areas of Bombay. X International Conference on AIDS. Yokohama, August 1994 [abstract 0457].
51. Msiska R: *An Intervention Study to Develop and Test the Benefit of an Enabling Approach in Reducing HIV Transmission in a Fish Trading Community in Zambia*. Lusaka: National AIDS Programme; 1994.
52. Schuler SR, Hashemi SM: Credit programs, women's empowerment and contraceptive use in rural Bangladesh. *Stud Fam Plann* 1994, 25:65-76.
53. Ankrah EM: AIDS: methodological problems in studying its prevention and spread. *Soc Sci Med* 1989, 29:265-276.
54. Hepburn M: Prostitution: would legislation help? *BMJ* 1993, 307:1370-1371.
55. Pascal CB: Intravenous drug abuse and AIDS transmission: federal and state laws regulating needle availability. *NIDA Res Monogr* 1988, 8:119-136.
56. Chappel D, Reitsma T, O'Connell D, Strang H: Law enforcement as a harm reduction strategy in Rotterdam and Merseydide. In *Psychoactive Drugs and Harm Reduction: From Faith to Science*. Edited by Heather N, Wodak A, Nadelmann E, O'Hare P. London: Whyr Publishers Ltd; 1992:118-126.
57. Broers B: Drug policy and the effect on HIV prevalence in the Swiss context [letter]. *Int J Drug Policy* 1994, 4:226-227.
58. Schilts R: *And the Band Played On: Politics, People and the AIDS Epidemic*. New York: St Martin's Press; 1987.
59. Editorial: Cities and states: a careful balance of responsibilities — interviews with J.F. Muller and L. Fournier (in French). *Le Journal du SIDA* 1994, 67:35-36.
60. O'Hare P, Newcombe R, Mathews A, Buning E, Drucker E: *The Reduction of Drug-related Harm*. London: Routledge; 1992.
61. Des Jarlais DC, Friedman SR, Friedman P, et al.: HIV/AIDS-related behavior change among injecting drug users in different national settings. *AIDS* 1995, 9:611-617.
62. Dubois AF, Jeannin A, Meystre-Agostino G, Gruet F, Paccaud F: Prevention of AIDS in drug addicts in Switzerland: an encouraging development [in German]. *Schweiz Rundsch Med Prax* 1994, 8:916-920.
63. Huber C: Needle park: what can we learn from the Zurich experience? *Addiction* 1994, 89:513-516.
64. Rihs-Middel M: The prescription of narcotics under medical supervision and research relating to drugs at the Federal Office of Public Health. In *The Medical Prescription of Narcotics*. Edited by Lewis D, Gear C, Rihs-Middel M. Fribourg, Switzerland: Huber Verlag; 1995 (in press).
65. Rojanapithayakorn W: *100% Condom Policy: Measures for AIDS Control in Thailand*. Bangkok: Ministry of Public Health; 1991.

66. Hanenberg RS, Rojanapithayakorn W, Kunasol P, Sokal DC: Impact of Thailand's HIV-control programme as indicated by the decline of sexually transmitted diseases. *Lancet* 1994, 344:243-245.
67. Olowo-Freers B: Socio-cultural aspects of sexual behavioural practices that contribute to the transmission of HIV/AIDS in Uganda. Kampala: UNICEF; 1992.
68. De Bruyn M: Women and AIDS in developing countries. *Soc Sci Med* 1992, 34:249-262.
69. Standing H, Kisekka MN: *Sexual Behaviour in Sub-Saharan Africa*. London: ODA; 1989.
70. Berer M, Ray S: *Women and HIV/AIDS*. London: Pandora; 1993.
71. Martin DJ: Community activities network as a method for maintaining reduced-risk for HIV infection in gay men. *IV International Conference on AIDS*. Stockholm, June 1988 [abstract 4075].
72. Epstein WM: British moralities, Hong Kong realities. *Society* 1994, 31:49-53.
73. Over M, Piot P: HIV infection and other sexually transmitted diseases. In *Evolving Health Sector Priorities in Developing Countries*. Edited by Jamison DT, Mosley WM. Washington, DC: World Bank; 1990.
74. Booth RE, Walters JK: How effective are risk-reduction interventions targeting injecting drug users? *AIDS* 1994, 8:1515-1524.
75. Peterman TA, Aral SO: Evaluating behavioral interventions: need for randomized controlled trials [letter]. *JAMA* 1994, 271:1317-1318.
76. Chen H-T, Rossi HR: Evaluating with sense: the theory-driven approach. *Eval Rev* 1983, 7:283-302.

5

MATERIAL ON HIV/AIDS

SENT BY

**MEDICAL MISSION INSTITUTE
AIDS AND INTERNATIONAL HEALTH DEPARTMENT**

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

TABLE OF CONTENTS

Executive Summary	1
Introduction	2
Part 1: Risk of HIV transmission in the health care setting	4
1.1 HIV transmission in health care settings	4
1.2 Transmission from patient to patient	5
1.3 Transmission from patient to health care worker	5
1.4 Transmission from health care worker to patient	7
1.5 Reporting exposures	8
Part 2: Prevention of HIV transmission in the health care setting	9
2.1 Universal precautions in practice	9
2.2 Safe handling and disposal of sharps	10
2.3 Safe decontamination of instruments and other contaminated equipment	14
2.4 Handwashing	17
2.5 Use of protective barriers	18
2.6 Safe disposal of waste contaminated with body fluids	21
2.7 Safe handling of specimens	22
Part 3: Universal precautions: planning, policy and practice	23
3.1 Responsibility for “universal precautions”	23
3.2 Risk assessment	24
3.3 Risk reduction strategies	24
3.4 Setting policy	25

3.5	Setting priorities	26
3.6	Staff training	28
3.7	Estimating supply needs	29
3.8	Obtaining supplies through various channels	32
3.9	Monitoring compliance and standards of practice	32
3.10	Quality assurance	33
3.11	Record-keeping	33
	Glossary	35
	Annex 1. Classification of exposures	37
	Annex 2. Example of a standard operating procedure for sharps injuries	39
	Annex 3. Example of an infection control standards checklist (audit tool)	41
	Additional reading	43

EXECUTIVE SUMMARY

HIV has been isolated from blood, semen, vaginal secretions, saliva, tears, breast milk, cerebrospinal fluid, amniotic fluid and urine, and is likely to be present in other body fluids. However, blood is the only fluid known today to be associated with HIV transmission in the health care setting. The risk of transmitting HIV and other bloodborne diseases depends on health personnel practices, the prevalence and transmissibility of the bloodborne organism, and the amount or frequency of exposure.

The occupational risk of acquiring HIV infection from patients in health care settings is low and in most cases is associated with needle-stick injuries from a patient with HIV infection. Patient-to-patient transmission results primarily from contaminated equipment that has been incorrectly disinfected or from blood transfusions. Most patient care does not involve any risk of HIV transmission, and routine HIV testing of health care workers or patients is not recommended.

To minimize the risk of occupational transmission of HIV, all health care workers should adopt appropriate infection control, risk assessment and accident prevention procedures. These can be summarized as follows:

- Universal precautions should be understood and used with all patients at all times by all health care personnel;
- Reducing unnecessary injections, suturing and unnecessary blood transfusions should be a goal for all health care settings;
- All health care settings and health programmes should make available adequate supplies necessary to comply with simple standards of infection control and designed to minimize potential opportunities for occupational HIV transmission;
- Active and locally appropriate policies and guidelines should be adopted for the proper use of supplies and a programme of staff education and supervision initiated.
- Risk assessment and risk reduction should become a regular part of supervision in health care settings.

INTRODUCTION

The HIV/AIDS pandemic has highlighted a number of public health problems, one of which is the transmission of bloodborne viruses in health care settings. Even if limited resources are available, simple infection control measures can be implemented to minimize this risk of transmission.

The primary goal of any infection control policy for the prevention of HIV transmission in the health care setting is to prevent the spread from patient to health care worker, from health care worker to patient and from patient to patient. These infection control measures must be practical to implement and enforce; they must be economically feasible; and they should pose a minimal risk of adverse medical, legal or social consequences for the patient, health care worker, or institution.

Who is the guide for?

This guide is written for health service supervisors responsible for the implementation of effective infection control practices in health care settings.

What is the guide about?

This guide provides:

- a practical and simple approach to infection control in the care of **all patients**, including those who may be infected with bloodborne viruses;
- advice on introducing and initiating a policy for universal precautions;
- information on how to set priorities and plan for supplies to implement universal precautions.

How is this guide organized?

Part 1:

Risk of HIV transmission in the health care setting.

This section provides a general overview of the risk of HIV transmission in the health care setting.

Part 2:

Prevention of HIV transmission in the health care setting.

This section provides practical information on the principles of good infection control practice, which can be applied to different types of health care settings.

Part 3:

Universal precautions: planning, policy and practice

This section provides a step-by-step approach on how to set priorities, establish policies and plan for supplies. It includes suggestions for calculating requirements and ordering supplies.

The principles for the prevention of transmission of HIV are the same as for hepatitis B and other bloodborne pathogens. However, this guide focuses on preventing the transmission of HIV. It does not deal with issues related to possible transmission of bloodborne viruses acquired through blood transfusion, nor the legal and ethical implications of an occupationally acquired infection.

This guide may supplement national guidelines already in use in health care settings.

Part 1: RISK OF HIV TRANSMISSION IN THE HEALTH CARE SETTING

The incidence of HIV infection continues to increase throughout the world. HIV is principally transmitted by sexual intercourse, but may also be acquired through exposure to infected blood or blood products and from an infected mother to her child. There is good evidence that HIV cannot pass through intact skin and that it is not transmitted by close social contact.

Body fluids which can transmit HIV include: blood, semen, vaginal and cervical secretions, wound secretions, cerebrospinal fluid, pleural fluids, synovial, peritoneal, pericardial and amniotic fluids, breast milk, and other body fluids containing visible blood.

1.1 HIV transmission in health care settings

Blood is the single most important body fluid involved in the transmission of HIV infection in health care settings.

HIV can be transmitted in health care settings in the following ways:

- **to patients**
 - contaminated instruments (needles, syringes, scalpels and other instruments used in invasive procedures) that are re-used without being adequately disinfected or sterilized;
 - transfusion with HIV-infected blood;
 - skin grafts, organ transplants or donated semen from an HIV-infected donor;
 - contact with blood or other body fluids from an HIV-infected health care worker.

■ **to health care workers**

- injury with a needle or any other sharp instrument which has been contaminated with blood or other body fluids from an HIV-infected person;
- exposure of open wounds to blood or other body fluids from an HIV-infected person;
- splashes of infected blood or body fluids onto mucous membranes, e.g. in the mouth, and the eyes.

1.2 Transmission from patient to patient

In general, transmission of HIV in the health care setting between patients is uncommon. It is usually related to HIV-contaminated blood transfusions where screening of donated blood is not carried out. HIV transmission has also occurred via HIV-contaminated needles and instruments and equipment which are not properly cleaned, disinfected or sterilized between use. In settings with limited supplies and equipment, there may be widespread use of such improperly cleaned and sterilized medical, dental and traditional instruments due to, for example, inadequate boiling time, or repeated use of the same syringe and needle with no sterilization.

There is **no** risk of HIV transmission between patients through casual contact, such as sharing clinic waiting areas, bathrooms, dining rooms or eating utensils.

1.3 Transmission from patient to health care worker

The majority of health care workers experience some kind of needle-stick injury each year, and for many these incidents occur frequently. A certain proportion of these exposures are to HIV-infected blood. The greatest risk of HIV infection is from sharps injuries with HIV-contaminated hollow needles. Injuries from suture needles, lancets, scalpels or other sharp items also carry some risk.

It is clear that exposure to blood presents the greatest risk to health personnel.

Although the risk of infection following percutaneous exposure is real, it is small. Indications are that the risk from a sharps injury with HIV-positive blood will result in HIV infection ranges from 1 in 250 (0.4%) cases to 1 in 300 (0.3%) cases. A susceptible health care worker who is exposed to hepatitis B virus following a needle-stick injury has a much higher risk of acquiring hepatitis B infection. However, protection against hepatitis B virus disease can be offered through vaccination (see the following table 1).

Risk of transmission of bloodborne viruses to health care workers	
Human immunodeficiency Virus (HIV) Percutaneous exposure Mucocutaneous exposure	0.4% (low) 0.05% (lowest)
Hepatitis B virus (HBV) Percutaneous exposure	9 – 30% (high)
Hepatitis C virus (HCV) Percutaneous exposure	3 – 10% (moderate)

Very few cases of occupational HIV transmission have been reported after exposure of mucous membranes (mouth and eyes) or broken skin to infected blood. The risk of acquiring HIV infection by this route is much lower than the risk from percutaneous exposure, and work-related HIV infection is believed to be uncommon. Nevertheless, continuing efforts must be made to minimize any possible transmission from patient to health care worker.

While wearing gloves may reduce the risk of being infected by a needle-stick injury, it is very important to note that the use of gloves does not prevent sharps injuries or cuts. Therefore, efforts to prevent HIV transmission from such accidents must focus first on preventing injury from needles and other sharp objects, and second on the safe handling and disposal of these items.

1.4 Transmission from health care worker to patient

The majority of routine procedures in the health care setting present no risk of HIV transmission and the risk of transmission from HIV-infected health care workers to patients is remote. Provided health care workers properly use the standard infection control measures, the circumstances in which HIV could be transmitted to a patient are restricted to exposure-prone procedures, where an injury to the health care worker could cause his/her blood to enter the patient's tissues.

HIV-infected health care workers should therefore avoid performing exposure-prone procedures. They may perform other procedures which do not pose a risk of transmission to patients, where the hands and fingertips of the worker are visible and outside the patient's body at all times, or where sharp instruments are not required, e.g. assisting in childbirth, internal examinations, taking blood and insertion of intravascular catheters.

In midwifery practice, normal vaginal delivery in itself is not an exposure-prone procedure. However, HIV-infected health care workers should avoid procedures involving the use of sharp instruments, since the fingertips may not be visible at all times and the risk of injury to the worker is greater. Instrumental delivery requiring infiltration of local anaesthetic or internal suturing presents the same increased risk of transmission.

A health care worker with HIV infection who **does not** perform exposure-prone procedures **does not** pose any risk to patients, provided that the worker complies with universal precautions.

Part 2: PREVENTION OF HIV TRANSMISSION IN THE HEALTH CARE SETTING

The risk of transmission of bloodborne pathogens in the health care setting cannot be eliminated but can be minimized by preventing exposure to infected blood and body fluids. Universal precautions are a set of particular recommended practices which when used correctly will minimize unnecessary exposure to blood and body fluids.

Universal precautions aim to ensure that the accidental exposure of patients and health care workers to potentially infectious blood is reduced to the absolute minimum.

2.1 Universal precautions in practice

Universal precautions are based on the assumption that all blood is potentially infectious, regardless of whether it is from a patient or health care worker, regardless of their known HIV antibody status, and should be applied in the care of all patients.

The precautions apply to the body fluids which may contain HIV. Other body fluids such as faeces, urine, sputum, vomit, saliva, while not associated with the transmission of HIV, may contain other pathogens and the risk of cross-infection may be reduced if simple infection control practices are applied.

Universal precautions consists of 5 standard practices:

- safe handling and disposal of sharps;
- safe decontamination of instruments and other contaminated equipment;
- handwashing;
- use of protective barriers to prevent direct contact with body fluids;
- safe disposal of waste contaminated with body fluids.

1.5 Reporting exposures

Health care workers should be encouraged to report exposures to the appropriate authority in the institution immediately after they occur; however, many health care workers fail to report work-related accidents or HIV exposures. There are many reasons offered for not reporting such accidents: they are too busy; the reporting procedure requires attendance at a distant office at difficult times; they may feel that it will not make a difference to the outcome. However, health care workers who do report work-related accidents or exposures stand a better chance of benefiting from insurance, health care and other provisions related to the terms and conditions of work. Failure to report occupational exposures creates a false impression about the degree of risk faced by health personnel and the frequency of these exposures.

The record should contain the following information:

- employee identification;
- date, time and place of the exposure;
- details of the exposure, including amount and type of fluid or material and severity of exposure (see Annex 1);
- circumstances surrounding the exposure;
- actions taken, including counselling and medical evaluation for any acute illnesses that occur during the follow-up period.

The record should be made and kept in a manner that protects confidentiality and is in accordance with national and institutional regulations.

2.2 Safe handling and disposal of sharps

The greatest risk of bloodborne pathogen transmission in health care settings is through percutaneous exposure. Efforts to prevent transmission must focus on preventing injury from contaminated sharp instruments by encouraging safe handling and disposal of sharps. Most sharps injuries associated with HIV transmission involve deep injuries with hollow-bore needles. These injuries frequently occur when needles are recapped, cleaned, disposed of, or inappropriately discarded, e.g. used needles left on trolleys or beds.

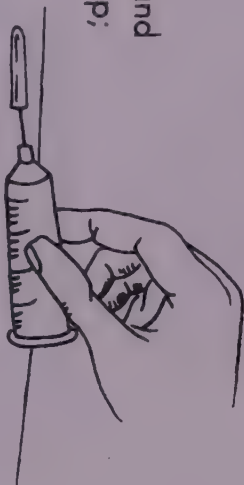
Single-handed capping

Recapping needles is sometimes unavoidable, and in this case the single-handed scoop method should be utilized. Recapping a needle with two hands increases the likelihood of sustaining a sharps injury. To recap a needle, using a single hand:

- (a) Place needle cap on a hard flat surface and remove hand;



- (b) With one hand, hold syringe and use needle to scoop up the cap;



- (c) When the cap completely covers the needle, use the other hand to place cap firmly on the needle hub.



All sharps should be handled with extreme care at all times and their use should be kept to the minimum. Puncture-resistant disposal containers must be available for the disposal of sharps and must be located as close to the point of use as possible. Sharps disposal containers can be made of easily available objects, e.g. a tin with a lid, a thick plastic bottle, or a heavy cardboard box.

Syringe incinerator boxes are boxes that protect the health worker from contaminated equipment. Used plastic syringes and needles must be placed carefully in the boxes, which are then burned. Alternatively, the boxes can be used to transport used equipment to an incinerator.

Sharps containers are often overfilled, with sharps sticking out from the top. In order to reduce risk of transmission when discarding disposable sharps, health personnel should always:

- empty sharps containers when three-quarters full;
- wear heavy-duty gloves when transporting sharps containers;
- incinerate used equipment at a sufficient temperature to melt the needles;
- bury the sharps container after incineration.

See also the following box.

Sharps accidents

Each health facility should develop standard operating procedures to be followed by all health personnel in the case of sharps injury or other exposure. An example of a standard operating procedure can be seen in Annex 2.

Most experts agree that the larger the volume of blood involved in the exposure, the greater the risk of infection. Therefore first aid must begin as soon as possible after the exposure and aim to flush away as much inoculum as possible. Where there is minor bleeding, the wound should be allowed to bleed briefly. Then the wound and surrounding skin should be washed with soap and clean water, preferably running water. Exposed mucous membranes should be washed with large amounts of water. The use of antiseptic solutions as substitutes for water has not been proved to have any advantage and is not recommended because of the possible caustic effect. In the absence of water, antiseptic solutions would have some merit.

If the same accidental exposure occurs more than twice, the working procedure should be reviewed. For example, staff training may be required, or more sharps disposal containers may need to be made available.

Evaluating sharps practices

Risk of injury should be assessed when evaluating sharps practices to establish if there is a safer way to undertake procedures. These could include using skin staples for skin closure, using adhesive tape or skin closure strips for suturing superficial lacerations, giving medication orally rather than by injection and avoiding making unnecessary incisions, e.g. routine episiotomy.

Good practice for the safe handling and disposal of sharps

- **ALWAYS** dispose of your own sharps. **NEVER** pass used sharps directly from one person to another; this practice should be followed by **all** health care workers;
- During exposure-prone procedures, the risk of injury should be minimized by ensuring that the operator has the best possible visibility, e.g. by positioning the patient, using as good a light source as possible and controlling bleeding;
- Protect fingers from injury during suturing by wearing gloves and using a gauze or cotton wool pad;
- Never recap, bend or break disposable needles.
- Directly after use, store needles and syringes in a rigid container until ready for decontamination;
- Locate sharps disposal containers close to the point of use, e.g., patient's room, on the medicine trolley, treatment room;
- Dispose of, and transport sharps in a puncture-resistant container. **NEVER** place used sharps in other waste containers;
- Keep all sharps and sharps disposal containers out of the reach of children;
- Prevent overflow by sending sharps disposal containers for incineration when three-quarters full.

2.3 Safe decontamination of instruments and other contaminated equipment

As HIV can be transmitted via needles, syringes and other equipment contaminated with body fluids, these items should be cleaned and sterilized, or appropriately disinfected before each use. The method of decontamination for instruments and equipment depends on what they are used for and the associated level of risk of transmission (see the table below).

Selecting the method of decontamination		
level of risk	Items	Decontamination method
High –	Instruments which penetrate the skin/body	Sterilization Single use of disposable
Moderate –	Instruments which come into contact with mucous membranes or non-intact skin	Sterilization Boiling Chemical disinfection
Low –	Equipment which comes into contact with intact skin	Thorough washing

Efficient cleaning with detergent and hot water removes a high proportion of any microorganisms present. All equipment should be dismantled for thorough cleansing.

Heavy-duty gloves should be worn for cleaning instruments to reduce the risk of injury. If splashing of body fluid is likely, additional protective clothing should be worn, e.g. plastic aprons and protective spectacles.

Sterilization

All forms of sterilization will destroy HIV and hepatitis B and C viruses. The recommended methods of sterilization are described in the table below.

Recommended methods of sterilization	
* Steam under pressure (e.g. autoclave, pressure cooker) Required pressure: ⇒ 15 psi (101 kPa)	
Temperature 115°C 121°C 126°C 134°C	Time 30 minutes 15 minutes 10 minutes 3 minutes
* Dry heat (e.g. electric oven)	
Temperature 160°C 170°C 180°C	Time 120 minutes 60 minutes 30 minutes

Instruments that are unwrapped for sterilization quickly become contaminated with microorganisms on removal from the autoclave. Consequently, these instruments should either be used immediately following sterilization or stored in clean, dry conditions and re-sterilized when required for an invasive procedure.

Disinfection

Disinfection will usually inactivate HIV. Two commonly employed methods are boiling and chemical disinfection.

- Boiling is an effective way to disinfect equipment, e.g., needles and syringes, if autoclaving facilities are not available. Equipment which has first been cleaned should be boiled for 20 minutes.
- Chemical disinfection is used for heat-sensitive equipment that is damaged by high temperatures. Most disinfectants are effective against a limited range of microorganisms and vary in the rate at which they destroy microorganisms. Items must be dismantled and fully immersed in the disinfectant. Care must be taken to rinse disinfected items with clean water so that they do not become recontaminated. Chemical disinfectants are unstable and chemical breakdown can occur. They may also be corrosive and irritating to skin. Protective clothing may be required. Chemical disinfection is not as reliable as boiling or sterilization. However, the following will inactivate HIV:

- Chlorine-based agents, e.g., bleach
- 2% glutaraldehyde
- 70% ethyl and isopropyl alcohol.

Cleaning

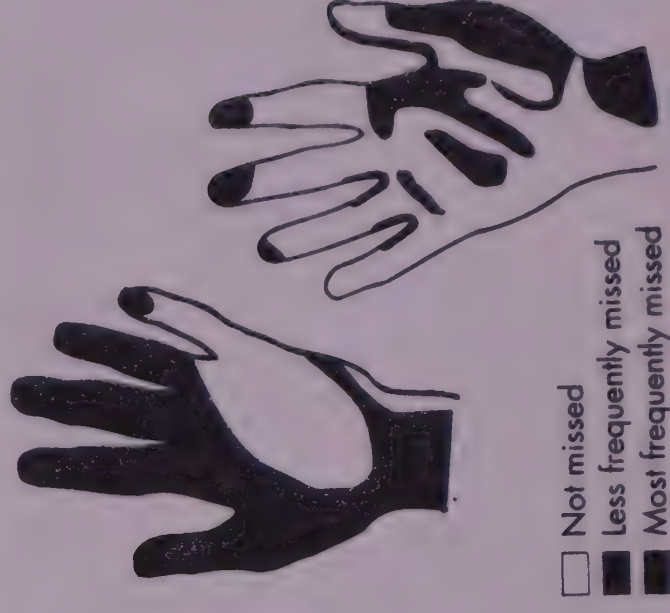
Detergent and hot water are adequate for routine environmental cleaning, e.g. floors, walls, toilets, beds, rubber draw sheets. Disinfectants are not necessary for routine cleaning.

Following a **spillage of body fluids**, heavy-duty rubber gloves should be worn and as much of the body fluid as possible removed with some disposable absorbent material, e.g. paper towels. This can then be discarded safely into a leak-proof container and incinerated. The area of spillage should be cleaned with a chlorine-based disinfectant and the area thoroughly washed with hot water and detergent.

2.4 Handwashing

The hands of health care workers are frequently responsible for the transmission of various infections between patients. Microorganisms acquired on the hands by contact with body fluids or contaminated surfaces can be readily removed by washing with soap and water. See also the following figure.

Areas most commonly missed in handwashing



- ☐ Not missed
- ☐ Less frequently missed
- ☐ Most frequently missed

Under ideal circumstances, hands should be washed at a basin with running water. However, handwashing, using a bowl of water and soap is still effective. If a re-usable towel is used to dry the hands, then it should be washed regularly.

HIV cannot pass through intact skin, but it is possible for infection to be acquired when blood is in contact with damaged skin. Hands should therefore be washed immediately if they become contaminated with body fluids. Cuts, abrasions or other damaged skin should be covered with a waterproof material while working in clinical areas. Since gloves often have invisible tears, hands should always be washed once gloves have been removed.

2.5 Use of protective barriers

Protective clothing should be worn where exposure to significant amounts of blood is anticipated. The protection selected will depend on the type of exposure anticipated. Where supplies of protective clothing are limited, priority should be given to procedures involving a high risk of exposure to blood. See also the following table.

Selection of protective clothing		
Type of exposure	Protective clothing required	Examples
Low risk of contact with small amount	* gloves helpful but not essential	injections, minor wounds
Contact with blood probable, splashing unlikely	* gloves * apron may be necessary to protect clothing	vaginal examinations, insertion or removal of intravenous cannula, handling laboratory specimens, large open wounds, venepuncture, spills of blood
Contact with blood probable, splashing uncontrolled bleeding likely	* gloves * fluid resistant gown or apron * eye protection * mask	major surgical procedures, oral surgery, vaginal delivery

Gloves

For most patient contact, if the amount of blood is small enough to be completely contained by a gauze or cotton swab, gloves are not necessary.

Latex or vinyl gloves should be worn for direct contact with blood or other potentially infected body fluids. Gloves should be worn when sharps are used. Although gloves will not prevent a sharps injury, wearing gloves has been shown to reduce the volume of the infectious material and may significantly reduce the risk of exposure to a patient's blood. For invasive procedures, gloves should be sterile, but for most other procedures gloves can be non-sterile.

Gloves should be discarded after each patient. If this is not possible, certain kinds of gloves can be washed and/or sterilized before re-use. Gloves with visible holes or tears should be discarded.

Heavy-duty rubber gloves should be worn for cleaning instruments, handling soiled linen or dealing with spills of body fluid. They can be washed and re-used many times.

Fluid-resistant gowns and aprons

Aprons should be worn to protect health care workers during procedures where splashing of blood or body fluids is anticipated, e.g. childbirth. During surgery, where there is a high likelihood of splashes with blood, the surgeon should wear a fluid-repellent gown or a sterile cloth gown with a plastic apron underneath.

Masks and protective eyewear

Although splashes to mucous membranes are relatively common, they do not represent a significant risk for HIV transmission and seroconversion is unlikely. The amount of exposure can be reduced through the use of masks and protective eyewear.

Protective eyewear should be washed if it becomes contaminated. Ordinary spectacles will provide adequate protection in most situations. Any re-usable protective clothing contaminated with body fluids should be washed thoroughly after use.

2.6 Safe disposal of waste contaminated with body fluids

Safe disposal of waste is an important infection control practice and is frequently poorly managed.

The following recommendations should be followed with all waste from health care settings. Heavy-duty gloves should be used by anyone transporting waste to the site of disposal. Eye protection should be used when disposing of liquid waste. Waste not contaminated with body fluids can be disposed of as general waste. See also the following table.

Waste category	End disposal
<ul style="list-style-type: none">* Waste that is contaminated with body fluids should be placed in a leak-proof bag or container* Laboratory/pathology waste and placentae should be placed into leak-proof containers	Incinerate or bury in a 7 feet deep pit at least 30 feet away from a water source
<ul style="list-style-type: none">* Liquid waste, e.g. blood	Pour down a drain connected to an adequately treated sewer or into a pit latrine

2.7 Safe handling of specimens

The principles of universal precautions apply equally in laboratories and for specimen handling. All specimens should be treated as potentially infectious, and transported in leak-proof containers with the request form protected from contamination. All personnel who transport specimens should know how to handle specimens safely and should have a practical understanding of universal precautions.

Part 3: UNIVERSAL PRECAUTIONS: PLANNING, POLICY AND PRACTICE

The use of universal precautions will minimize the risk of transmission of HIV and other bloodborne pathogens. However, each health care setting will vary in the level and type of risk, the available equipment and resources, and standards of practice. Health care workers tend to use universal precautions selectively and intermittently, and compliance with universal precautions is generally lower than is acceptable or desirable. It is the responsibility of the manager or supervisor to ensure that there is:

- consistent and strict use of universal precautions;
- constant modification of work practices to assure optimum safety in the workplace;
- all equipment is safe and operational.

3.1 Responsibility for universal precautions

A broad participatory base is essential to achieve better levels of compliance and comprehension regarding universal precautions. Even smaller health units such as health centres should comply with universal precautions and should have a degree of responsibility and a sense of ownership regarding the unit policy. To introduce and support the use of a policy of universal precautions, it is helpful to establish a group of individuals who can represent the entire health facility. The group should meet regularly and more than once a year.

This committee or group will be able to decide what the policy should be and how it should be implemented. These decisions may be influenced by practical issues, such as the available budget, equipment and personnel.

3.2 Risk assessment

It is clear that the practices of health care workers significantly affect the degree of risk of HIV transmission to patients and themselves. Needle-stick injuries are frequently related to both training and experience, with the type and frequency of injuries altering as staff increase their practical skill levels but also their exposure. Health care workers are also more liable to injuries when staffing levels are inadequate, when supervision is lacking or inadequate and when staff are tired or working in an unfamiliar area. Each manager and/or supervisor must be aware of the various areas of risk for their staff and patients. Some kind of risk assessment procedure should be carried out, and repeated at regular intervals. This can be done using simple checklists based on the five standard practices recommended for universal precautions (see Annex 3).

Risk assessment cannot rely simply on exposure incidents reported by health care workers. It is known that health care workers frequently under-report exposure for a variety of reasons. This means that supervisors and service managers often have a very unreliable picture of the types, causes and frequency of exposures. Therefore, surveys of practitioners and their practices need to be carried out. These need not be complicated or large but should adequately indicate the risks to be found in the health care settings.

3.3 Risk reduction strategies

There are three different strategies for reducing risks of transmission and they differ in cost, feasibility and impact.

- (1) **Increase the safety of the technology used.** By increasing the safety of equipment, such as introducing new equipment and dispensing with old or damaged equipment, the risk to other patients and to health care workers is significantly reduced. By introducing sharps containers, the risk of needle-stick injury is significantly reduced, and this could have high impact at a low cost.

- (2) **Control work practices.** This is more difficult to achieve than increasing the safety of the equipment used. Work practices vary tremendously and expose some health care workers to greater personal risk than others. There is also a situational element such as time of day, case load, or emergencies, which supervisors cannot always control. However, supervisors can try to keep occupational stress and fatigue to a minimum. Supervision can be increased in quantity and improved in quality, and result in improved work practices. Controlling work practices need not involve extra cost, and can have significant impact on reducing risk.

- (3) **Provide personal protection equipment.** The introduction of this level of protection will have the least impact on reducing the risk of HIV transmission. Many institutions and organisations focus on this strategy without adequate consideration of the relative impact and associated costs.

3.4 Setting policy

Setting policy is different from establishing procedures for a department or clinical area. A policy is usually a general statement about a course of action, and involves achieving agreement or consensus about how important universal precautions are to be in the work setting, who are to be the primary beneficiaries, and which risk reduction strategies are to take priority. A good policy statement evolves out of participatory processes based on sound evidence. The policy group or committee need to discuss who is at most risk in their facility, what is the cause of this level of risk, and what risk reduction strategy is going to have greatest impact, least cost and is most feasible. The policy should reflect the outcome of these discussions.

The following is a sample of a workplace policy statement on HIV transmission in the health care setting.

Risks related to patient-to-patient transmission will receive the highest priority. Strong emphasis on infection control practices in all staff appraisal. Staff who are HIV-positive should voluntarily avoid exposure-prone invasive procedures. Records on exposures will be introduced and reporting of accidents will be compulsory and confidential. Infection control will be a part of the continuing education programme for all staff. All staff are encouraged to work with the infection control committee to achieve greater workplace safety.

Policy statements need to be regularly reviewed and updated in the light of advances in research, changing circumstances and new technologies. Policies that are out of date can hinder high standards of infection control, and can increase the risk of HIV transmission in the health care setting.

3.5 Setting priorities

It is not always possible to fully implement universal precautions; therefore those precautions intended to protect the greatest number of patients from the greatest risk of infection should take priority. Priorities should be based on the estimated level of risk, and the estimated impact of any risk reduction strategy. The greatest risk of HIV transmission is from patient to patient, and measures that reduce that risk should take priority. Patient to health care workers offers the next most significant risk, and therefore should be the next priority.

Examples of setting priorities

The following examples illustrate what different supervisors considered important when setting priorities for the implementation of universal precautions in different departments.

Example: Universal precautions in a busy maternity unit

The unit conducts 200 deliveries on average each month. A risk assessment revealed the following results: 75% of midwives in the survey reported at least one needle-stick injury in the last month; only 15% of midwives had voluntarily reported any exposure, and those were all mucocutaneous splashes to the eye; there is no light source for suturing. As midwives/birth attendants have significant contact with blood and perform exposure-prone procedures, this department gives high priority to the provision of personal protective equipment to implement universal precautions. The supervisor decides that they need enough gloves to use for suturing, soap and water for handwashing, eye protection and an appropriate light source for suturing and a review of routine use of episiotomy. She discusses ways of implementing this with the staff. The staff are requested to record details of any needle-stick injury over a one-month period, when the supervisor will return to discuss their injuries, study their work practices, and decide how to change them.

Example: Universal precautions in an immunization clinic

On average, 30 infants and children are immunized each session. There are two health staff relying on boiling re-usable instruments. The main risk of infection in this clinic appears to be through the use of re-usable needles and syringes. The supervisor gives priority to improving disinfection and sterilization practices through the purchase of a new pressure cooker type sterilizer.

Example: Universal precautions in a hospital ward

As ward staff have contact with blood and other body fluids and handle used sharps, priority is for supplies of water and soap for handwashing and containers for the safe disposal of sharps. There may be potential for saving resources, for example, by using detergent for general cleaning rather than disinfectants. Cheaper, heavy-duty utility gloves, which can be re-used many times, can be introduced for general housekeeping and handling contaminated linen or equipment.

3.6 Staff training

The success of a universal precautions policy depends to a large extent on the quality of staff practices. Successful implementation therefore is dependent upon all staff knowing about and understanding the precautions they are expected to take. It should be acknowledged that staff may be working in difficult environments and emphasis should be on improvements to practices, not negative evaluation and criticism. Regular training sessions could be organized to update staff and orient new employees. Providing information to small groups of staff facilitates discussion of their problems and concerns. Staff may also be able to provide useful ideas and suggestions for improving the policy. Where possible, any training should be supplemented by local guidelines readily available in each clinical area, and effective supervision.

However well organized these approaches may be, only a minority of staff are reached in this way, and education is usually successful only in combination with audit and other sound infection control practices. Another way of achieving this is for infection control specialists or supervisors to visit each clinic or department regularly.

3.7 Estimating supply needs

The success of a universal precautions policy also partly depends on the provision of adequate and appropriate supplies. Accurate projections about future needs increase the chances of adequate supplies without interruption. Once the annual minimum requirements have been established, a decision is needed about how best to allocate resources for particular supplies. Further prioritization may be necessary if there is insufficient money in the budget. It should be noted that a small change in institutional practice can have a major impact on the demand for supplies, either upwards or downwards. Estimating supplies can be based on demand or on the supply available. The first task is to collect information about the numbers of procedures or tasks performed and the numbers of staff involved.

Demand-based model:

This model is demand-driven, that is, supplies are calculated on the basis of demand.

List the type of supplies needed and the minimum amount required per procedure. Then estimate the number of procedures per month or year, and calculate the supplies needed for one year. The following examples show how demand-based supplies could be calculated.

Example 1: A dental department

Each dentist needs a pair of gloves for each procedure, as well as masks, eye protection and plastic aprons. It is decided that the plastic apron and mask need only be changed when contaminated, with an estimated usage of one per session of treatments, but with additional supplies to be made available for unexpected events.

To calculate the minimum requirements for protective clothing it is necessary to determine how many dental procedures are performed in a month and how many sessions of treatment and how many dentists there are. The calculation would then be as follows:

Number of dental procedures per session per month multiplied by one pair of gloves for each procedure equals the total number of gloves needed per month (+ 10% for emergencies): $24 \times 8 \times 1 = 192 + 19.2 = 211$.

Number of dental sessions per month multiplied by one plastic apron for each session equals the total number of plastic aprons needed per month (+ 10% for emergencies): $24 \times 1 = 24 + 2.4 = 27$.

Number of dental sessions per month multiplied by one face mask for each session equals the total number of masks needed per month (+ 10% for emergencies): $24 \times 1 = 24 + 2.4 = 27$.

Number of dentists and dental assistants in the department multiplied by two sets of eye protection (e.g. eye shields) for each equals the total number of eye protection devices needed per year: $3 \times 2 = 6$.

Example 2: A maternity department

The committee has decided that a minimum of two pairs of gloves should be available for each normal delivery. This allows for one pair for vaginal examination and a second pair for delivery of the infant and removal of the placenta. Midwives need a clean apron for each delivery, but these can be cleaned and re-used and last approximately 6 deliveries. Eye shields and masks need to be available in each delivery room.

The minimum requirement for protective clothing can then be calculated using the following information:

Number of deliveries each year multiplied by two pairs of gloves equals the total number of gloves needed for each year: $500 \times 2 = 1000$.

Number of delivery rooms multiplied by two pairs of eye protection devices (e.g. eye shields) equals the total number of eye shields needed for each year: $3 \times 2 = 6$.

Number of deliveries each year divided by six equals the total number of aprons needed for each year (+ 10% for emergencies): $500 \div 6 = 84 + 8 = 92$.

Supply-driven model

Provision of supplies may be determined by annual budget figures which set a maximum ceiling on what can be spent on necessary supplies for implementing universal precautions. Alternatively, an institution or facility may issue certain supplies on the basis of bed capacity or population size in the district, or percentage of the total centre budget. It is necessary to select the priority precautions to be implemented, some of which may be low-cost or cost-free, such as provision of sharps containers, and allocate on the same basis as used when calculating demand. Continuous or repeated setting of priorities may be necessary. Where there is a problematic gap between available supplies and level of demand, supervisors and managers need to be innovative and creative in problem-solving. Increasing supplies is not always the solution to improving universal precautions and reducing risk.

3.8 Obtaining supplies through various channels

When possible, order just what you need until the next supply date so that supplies are used "just in time". Damage can be prevented if supplies, for example gloves, are used promptly, instead of being stored for several months.

Institutional supply: Find out what can be obtained through regular institutional distribution systems. Enough needs to be ordered to allow regular operations within one supply period, that is, the time interval between deliveries of supplies. Reserve stocks should be maintained to allow for late deliveries. The WHO Global Programme for Vaccines and Immunisations generally estimates necessary reserve stocks at 10% of the equipment needed for one supply period, or one month's supply.

Non-institutional supply: Regular distribution channels can be supplemented through less formal channels, such as community action groups, self-help groups, local businesses and consumer groups. These supplies tend to be less regular and more difficult to coordinate but can be a valuable addition to the stocks. Sometimes exchanges with another hospital or health clinic are possible if there are surplus supplies. It may be possible to buy items and charge nominal fees, or ask users of a service to purchase from private merchants. A local shopkeeper might expand stock to include basic health supplies.

3.9 Monitoring compliance and standards of practice

Compliance and work practices can be evaluated in clinical areas to assess whether staff are observing the recommended precautions. For example, the observer could check to see if sharp instruments are being discarded or re-processed correctly, that protective clothing is available and being used appropriately, and that water and soap are available for handwashing. It is also important to identify inappropriate use which results in waste and indicates a poor

understanding of the policy, such as double-gloving or wearing gloves to change linen. Where staff fail to implement the precautions properly, a review of equipment provision and training needs can help to resolve the problem. Monitoring should be carried out regularly. It may help to develop checklists of required standards for the use of equipment and infection control practices to be monitored. Actual clinical practice can then be evaluated against these standards. An example is available in Annex 3.

3.10 Quality assurance

It is important to consider the quality of the supplied protective equipment and other items. Quality can be affected by storage conditions and supplies must be stored properly to ensure that they are available as and when needed. In general, high temperatures, humidity and sunlight contribute to rapid deterioration. Store supplies so they will be used on a "first in – first out" basis, that is, so that "older" supplies will be used before those newly received. It is important to monitor whether the storage system is being correctly followed. It will be fairly easy to improve on incorrect procedures. Supervisors can also regularly sample gloves and other items in use, to ensure that they do not show obvious signs of deterioration.

3.11 Record-keeping

Maintain accurate records of supplies related to infection control. These records can be used to estimate future supply needs and to identify problems in the flow and frequency of use of this equipment. If stocks exceed demand or demand exceeds stocks, it may be useful to conduct an audit to see why this discrepancy exists. If this is something you can change, decide on the appropriate action.

Records of occupational exposures may be important for administrative, insurance and legal decisions. The records form part of any management information system and it is essential that records are accurate, kept safely and can be retrieved as necessary.

GLOSSARY

Cleaning

The physical removal of most microorganisms and contamination, using detergent and water

Disinfection

The inactivation of vegetative bacteria, viruses and fungi, but not spores

Exposure-prone procedures

Procedures where there is a risk that injury to the health care worker may result in the exposure of the patient's open tissues to the blood of the worker. For example, where the worker's hands may be in contact with sharp instruments, or sharp tissues (teeth, bone) inside a patient's open body cavity, wound or confined anatomical space (e.g., perineal repair), where the hands may not be completely visible at all times

Health care workers

The people involved with providing health care services, including nurses, midwives, doctors, dentists, laboratory workers and others

Inoculation

Injection of a substance through the skin

Mucocutaneous exposure

Exposure of the mucous membranes (mouth and eyes) or non-intact (broken) skin to infected blood

Policy

A written statement used to guide and determine present and future decisions about standard operating procedures

Percutaneous exposure

Exposure occurring as a result of piercing the skin

Sharps

Any object which can penetrate the skin, including needles, scalpels, lancets, broken glass

Sharps injury

Any injury sustained by a health care worker which has been caused by a used sharp instrument

Sterilization

The complete destruction of all microorganisms, including spores

**Annex 1:
CLASSIFICATION OF EXPOSURES**

Exposure is contact with blood (or body fluids contaminated with blood). Exposure may be classified as follows:

Non-parenteral exposure

- Intact skin visibly contaminated with blood or body fluid.

Doubtful parenteral exposure

- Intradermal ("superficial") injury with a needle considered not to be contaminated with blood or body fluid;
- A superficial wound not associated with visible bleeding produced by an instrument considered not to be contaminated with blood or body fluid;
- Prior wound or skin lesion contaminated with a body fluid other than blood and with no trace of blood, e.g. urine.

The following exposures should be taken seriously and appropriate care and follow-up provided.

Possible parenteral exposure

- Intradermal ("superficial") injury with a needle contaminated with blood or body fluid;
- A wound not associated with visible bleeding produced by an instrument contaminated with blood or body fluid;
- Prior (not fresh) wound or skin lesion contaminated with blood or body fluid;
- Mucous membrane or conjunctival contact with blood.

Definite parenteral exposure

- Skin penetrating injury with a needle contaminated with blood or body fluid;
- Injection of blood/body fluid not included under "massive exposure";
- Laceration or similar wound which causes bleeding and is produced by an instrument that is visibly contaminated with blood or body fluid;
- Any direct inoculation with human immunodeficiency virus (HIV) tissue or material likely to contain HIV/hepatitis B virus (HBV) or hepatitis C virus (HCV) not included above – this refers to accidents in laboratory settings.

Massive exposure

- Transfusion of blood;
- Injection of large volume of blood/body fluids (> 1 ml);
- Parenteral exposure to laboratory specimens containing high titre of virus.

Adapted from American Nurses Association Position Statement on Post Exposure Programs in the Event of Occupational Exposure to HIV/HBV. Washington 1993.

Annex 2: EXAMPLE OF A STANDARD OPERATING PROCEDURE FOR SHARPS INJURIES

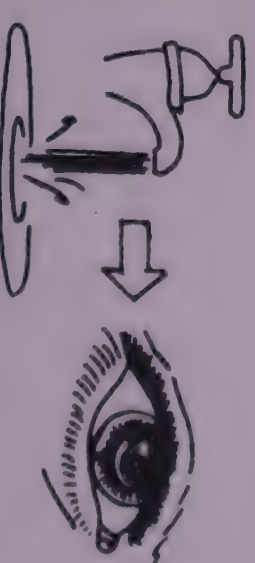
SHARPS INJURIES OR EXPOSURE TO BLOOD AND BODY FLUID

In case of injury with a used needle or other sharp or if bloody/body fluid is splashed into mouth, eyes or onto broken skin, carry out the following procedure.

1. Needlepricks, cuts, bites or scratches.
 - a) Encourage bleeding by squeezing.
 - b) Wash thoroughly with soap and water.
 - c) Cover with a waterproof dressing.



2. Splashes to mouth or eyes. Rinse thoroughly with plenty of running water.



- 3. Inform your manager immediately.
- 4. Complete the Accident/Incident Form. If known, include the name of the patient from whom the sharp/body fluid came.
- 5. Report to the Accident and Emergency department for further advice.

It is the responsibility of the member of staff involved and the manager to see that this procedure is carried out.

Annex 3:
EXAMPLE OF AN INFECTION CONTROL STANDARDS CHECKLIST (AUDIT TOOL)

Standard 1	Sharps are handled safely to minimize the risk of sharps injury Appropriate puncture-proof sharps container Container less than three-quarters full Sharps are not protruding from container One-handed recapping
Standard 2	Instruments decontaminated fully Sterilizer available and in good working order Equipment thoroughly cleaned after use Clean instruments in store cupboards
Standard 3	Hands are washed appropriately to prevent cross infection Soap and clean water available Clean towels available Staff observed to wash and dry hands after contact with body fluid, removal of gloves, contact with patients

cont'd...

Standard 4	Protective clothing is worn to prevent exposure to blood The following protective clothing is available for use by staff (depending on the clinical area and risk of exposure): <ul style="list-style-type: none">- Disposable gloves- Heavy-duty gloves- Masks- Aprons
Standard 5	Waste disposed of safely Evidence of deep burial or burning regularly No contaminated waste visible

ADDITIONAL READING

Detailed information about cleaning and sterilizing equipment is available in the following WHO publications:

EPI/PHW/84.2/Rev.1 (1987) "Immunization in Practice: A Guide for Health Workers Who Give Vaccines, No. 2: Syringes, Needles and Sterilization"

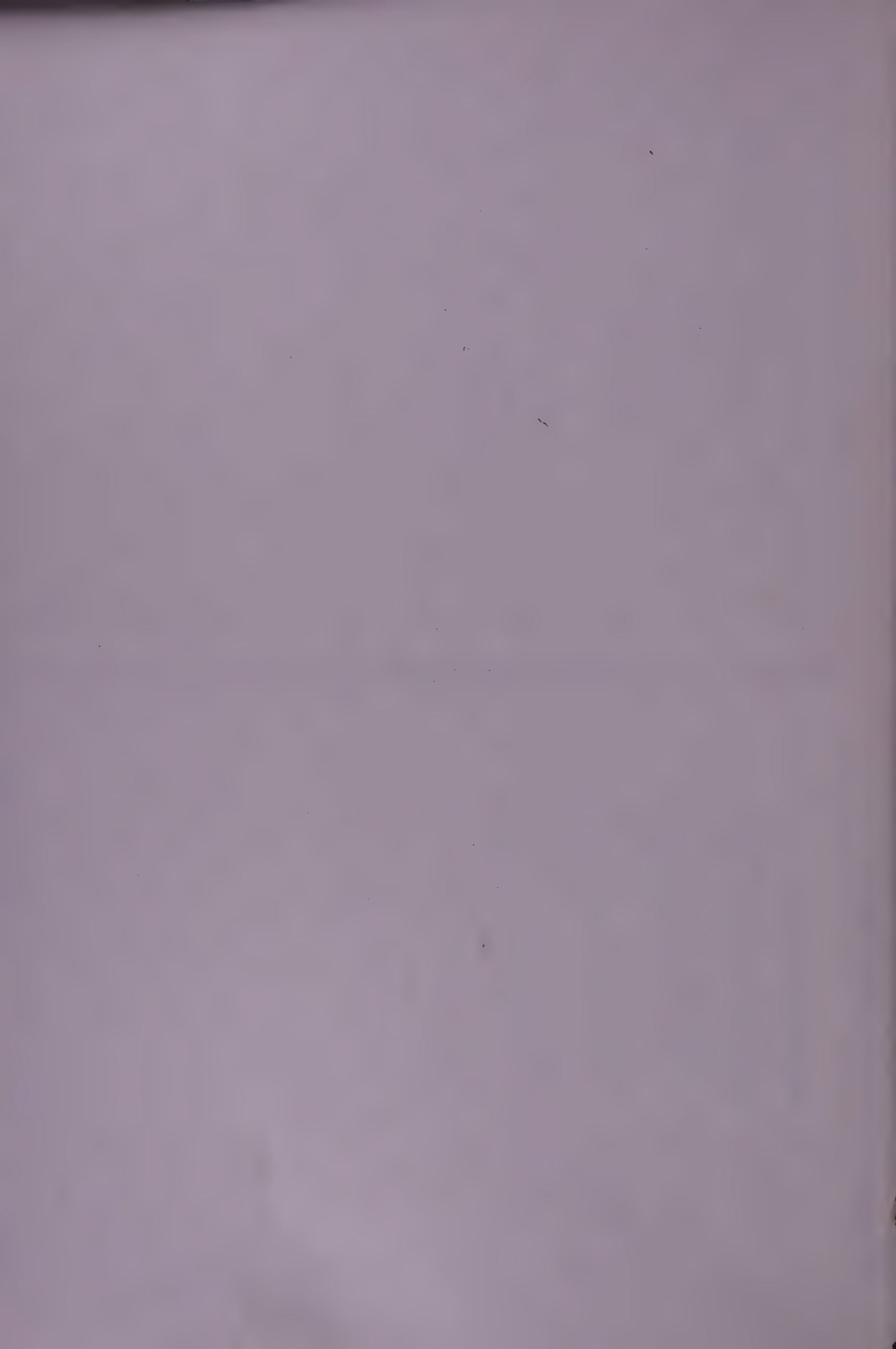
WHO/EPI Booklet CCXT/1/Rev. (1990) "How to Boil Needles and Syringes Properly"

WHO AIDS Series 2, (2nd edition, 1989), "Guidelines on Sterilization and Disinfection Methods Effective against Human Immunodeficiency Virus (HIV)"

EPI Update 5, 1987. Sterilization Alert

EPI Update 27, 1994. Safe Injection Practices

HIV/AIDS Reference Library for Nurses, Vol. 3. Infection Control. WHO. Manila 1993.



6

MATERIAL ON HIV/AIDS

SENT BY

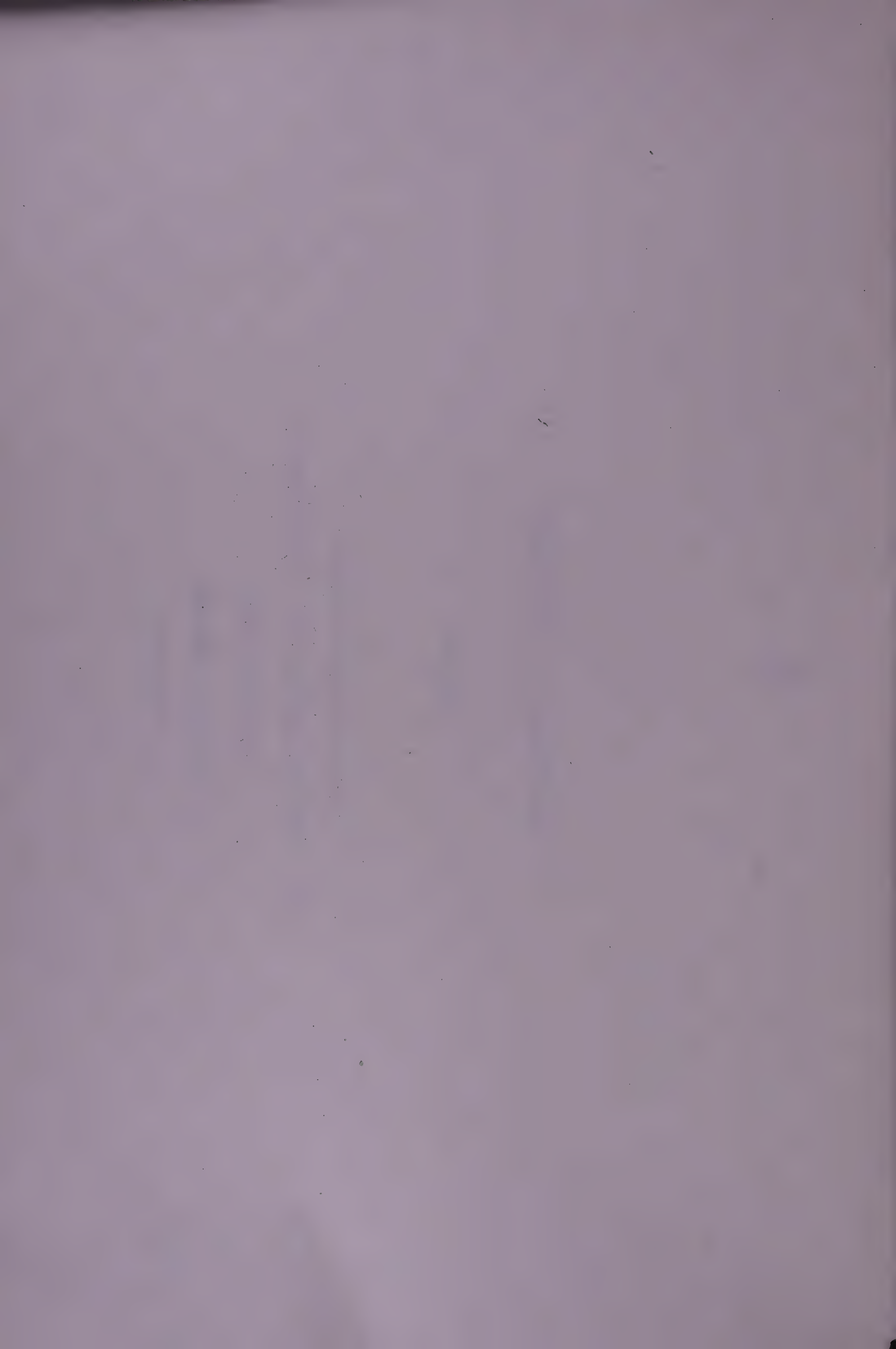
MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



TB/HIV

A CLINICAL MANUAL

Authors:

ANTHONY D. HARRIES
University of Malawi College of Medicine
Blantyre, Malawi

Global Tuberculosis Programme
World Health Organization
Geneva, Switzerland

DERMOT MAHER
Global Tuberculosis Programme
World Health Organization
Geneva, Switzerland

with contributions from:
LARIO C. RAVIGUONE, PIERRE CHAULET, PAUL P. NUNN
Global Tuberculosis Programme

and **ERIC VAN PRAAG**
Office of HIV/AIDS and STDs
World Health Organization
Geneva, Switzerland

and a foreword by **SIR JOHN CROFTON**
Professor Emeritus of Respiratory Diseases and Tuberculosis
University of Edinburgh, Scotland



World Health Organization
1996

CONTENTS

Foreword by Sir John Crofton	9
Introduction.	11
Glossary.	13
Ch.1. Background information on tuberculosis and on HIV	19
1.1 Tuberculosis	19
1.1.1 Basic facts about TB (M. tuberculosis, transmission, risk of progression to disease, natural history of untreated TB, epidemiology)	19
1.1.2 Pathogenesis (primary infection, postprimary TB)	20
1.2 HIV.	23
1.2.1 Introduction: HIV and AIDS	23
1.2.2 HIV/AIDS epidemiology.	23
1.2.3 HIV transmission	23
1.2.4 Prevention of HIV transmission in health units.	24
1.2.5 Immunopathogenesis of HIV infection	25
1.2.6 Natural history of HIV infection.	25
1.2.7 AIDS.	26
1.2.8 WHO case definitions for AIDS surveillance.	27
1.3 HIV-related TB.	29
1.3.1 Epidemiology	29
1.3.2 HIV infection and risk of TB	29
1.3.3 Consequence of HIV/TB co-infection.	30
1.3.4 Impact of HIV on TB control.	30
1.3.5 Patterns of HIV-related TB	30
1.3.6 Impact of TB on HIV.	31
Ch.2. Framework for effective tuberculosis control.	33
2.1 Introduction	33
2.2 Components of TB control framework	33

The authors and contributors gratefully acknowledge the helpful comments and suggestions of Dr. Kevin De Cock and Dr. Robert Colebunders, who reviewed the manuscript.

Copyright © World Health Organization (1996)

This document is not a formal publication of the World Health Organization (WHO), and all rights are reserved by the Organization. The document may, however, be freely reviewed, abstracted, reproduced or translated, in part or in whole, but not for sale or for use in conjunction with commercial purposes.

The views expressed in documents by named authors are solely the responsibility of those authors.

Printed in Italy

Designer: Jatto Associati s.a.s. - Italy

Printer: Stabilimento Tipografico Ferreo s.r.l. - Romano Canavese (TO) - Italy



2.2.1	Objectives	33
2.2.2	Strategy	34
2.2.3	Targets	34
2.2.4	Policy package	34
2.2.5	Key features of NTP	35
2.2.6	Indicators of NTP progress in TB control	35
2.3	Directly observed therapy	35
Ch.3. Diagnosis of tuberculosis in adults		
3.1	Pulmonary TB	37
3.1.1	Diagnostic approach	37
3.1.2	Clinical features	37
3.1.3	Diagnostic sputum microscopy	38
3.1.4	Differential diagnosis of pulmonary TB	41
3.1.5	Chest X-rays in diagnosis	42
3.1.6	Patterns of disease in pulmonary TB	43
3.1.7	Differential diagnosis of chest X-ray findings	44
3.1.8	Distinguishing other HIV-related pulmonary diseases from pulmonary TB	45
3.2	Extrapulmonary TB	46
3.2.1	Diagnostic approach	47
3.2.2	TB lymphadenopathy	47
3.2.3	Miliary TB	49
3.2.4	TB serous effusions (pleural, pericardial, ascites)	49
3.2.5	TB meningitis	55
3.2.6	Other forms of extrapulmonary TB	58
3.2.7	Further information on spinal, gastrointestinal and hepatic TB	59
Ch.4. Diagnosis of tuberculosis in children		
4.1	How does TB in children differ from TB in adults?	61
4.2	Approach to diagnosis of TB	62
4.3	Score system for diagnosis of TB in children	63
4.4	"Treatment trial"	65
4.5	Tuberculin test	65
4.6	Impact of HIV on diagnosis of TB in children	66

4.7	Differential diagnosis of pulmonary TB in HIV-infected children	67
4.8	Management of child contacts of infectious adults	67
Ch.5. Diagnosis of HIV infection in adults with tuberculosis		
5.1	Clinical recognition of HIV infection in adult TB patients	69
5.2	HIV testing	70
5.2.1	HIV tests	70
5.2.2	Objectives of HIV antibody testing in TB patients	71
5.2.3	Strategy for HIV antibody testing in TB patients	71
5.2.4	Diagnosis of HIV infection in individual TB patients	72
5.3	Counselling	72
Ch.6. Diagnosis of HIV infection in children with tuberculosis		
6.1	Clinical recognition of HIV infection in children with TB	75
6.2	HIV testing	76
6.3	Counselling	76
Ch.7. Standardised TB case definitions and treatment categories		
7.1	Standardised case definitions	79
7.1.1	Introduction	79
7.1.2	Questions and answers about case definitions	79
7.1.3	Case definitions by site and result of sputum smear	80
7.1.4	Case definitions by previous treatment	81
7.2	Standardised treatment categories	82
Ch.8. Treatment of TB patients		
8.1	Introduction	83
8.2	Mode of action of anti-TB drugs	84
8.3	TB treatment regimens	85
8.3.1	New cases	85



8.3.2	Retreatment cases	86
8.3.3	Standard code for TB treatment regimens	86
8.3.4	Recommended treatment regimens	87
8.3.5	Use of streptomycin and thiacetazone in areas of high HIV prevalence	88
8.4	TB treatment regimens: questions and answers	88
8.5	Use of anti-TB drugs in special situations: pregnancy, renal failure, liver disease	89
8.6	The role of adjuvant steroid treatment: questions and answers	90
8.7	Monitoring of TB patients during treatment	91
8.7.1	Monitoring of patients with sputum smear-positive pulmonary TB	91
8.7.2	Recording treatment outcome in sputum smear-positive patients	92
8.7.3	Cohort analysis: questions and answers	93
8.8	Response of HIV-positive TB patients to anti-TB treatment	93
Ch.9. Side effects of anti-TB drugs 95		
9.1	Introduction	95
9.2	Prevention of side-effects	95
9.3	Where to manage drug reactions	95
9.4	When to stop anti-TB drugs	95
9.5	Side-effects of anti-TB drugs	96
9.5.1	Side-effects of anti-TB drugs in HIV-positive TB patients	97
9.6	Symptom-based approach to management of drug side-effects	98

9.7	Management of itching/skin rash	98
9.7.1	Treatment regimen includes thiacetazone	99
9.7.2	Treatment regimen does not include thiacetazone	99
9.8	Desensitisation	101
9.9	Management of hepatitis	101
Ch.10. Management of other HIV-related diseases in TB patients 103		
10.1	Introduction	103
10.2	Sexually transmitted diseases	103
10.2.1	Syndromic management	103
10.2.2	Treatment regimens for common STDs	104
10.3	Skin and mouth problems	105
10.4	Gastrointestinal problems	107
10.4.1	Dysphagia	107
10.4.2	Diarrhoea	108
10.5	Respiratory problems	109
10.6	Neurological problems	111
10.6.1	Acute confusion	111
10.6.2	Chronic behaviour change	111
10.6.3	Persistent headache	112
10.6.4	Difficulty walking	113
10.6.5	Poor vision	114
10.6.6	Burning sensation in feet	114
10.7	Fever	115
10.7.1	Approach to management	115
10.7.2	Disseminated infection	115
10.8	Other HIV-related problems which may occur in TB/HIV patients	116

Doctors and other health professionals working in sub-Saharan Africa will be only too aware of the many patients they encounter with tuberculosis. They will also be all too well aware of the epidemic of HIV infection and the effect this has had on dramatically increasing the tuberculosis burden. They will know that in many patients development of clinical tuberculosis is the first sign of underlying HIV infection. This excellent book is designed for the busy clinician. It summarises the characteristics of both diseases and of their interactions. It concentrates particularly on the clinical problems of diagnosis and management, both in adults and children. It summarises the other HIV-related diseases which the clinician may encounter in TB/HIV patients. It provides a most useful review to those new to the problems and a handy reference for the experienced clinician when faced with some particular difficulty. It is well set out and easy to use.

The modern treatment of tuberculosis in HIV-infected patients is highly successful. This not only benefits the patient but reduces the spread of tuberculosis to families and the community. Other treatments can help to improve or control many HIV-related diseases. This book well summarises the range of treatments available. It also provides useful guides on counselling and on inter-agency cooperation, both essential components of TB/HIV management.

The enormous problems of HIV and tuberculosis in sub-Saharan Africa are now also increasing in Asia and South America, where the book should prove equally useful.

I congratulate WHO on deciding to produce this valuable book and the authors on the imaginative and practical way they have presented the problems and their management.

Sir John Crofton
Professor Emeritus of Respiratory Diseases and Tuberculosis
University of Edinburgh, Scotland



Ch.11. Coordinated care in different settings	119
11.1 Introduction	119
11.2 Benefits of support from local HIV/AIDS care services	119
11.3 Integrated system of HIV/AIDS and TB care	119
11.3.1 Referral to local HIV/AIDS care services	120
11.3.2 HIV counselling and voluntary testing centres	121
11.3.3 Care in the community	121
11.3.4 Care at Primary Health Care level	121
11.3.5 Private sector	121
11.3.6 Care at district level	122
11.3.7 Tertiary referral care	122
Ch.12. Prevention of TB in HIV-infected individuals	123
12.1 Introduction	123
12.2 Protection of HIV-positive persons against exposure to TB	123
12.2.1 Environmental control	123
12.2.2 Facemasks	124
12.2.3 Patient education	124
12.2.4 Pulmonary TB suspects	124
12.2.5 Patients with sputum smear-positive pulmonary TB	124
12.3 Role of BCG in preventing TB in HIV-infected individuals	125
12.3.1 Background	125
12.3.2 BCG protection against TB in HIV-infected children	125
12.3.3 BCG safety in HIV-infected children	125
12.3.4 WHO recommended policy on BCG and HIV	125
12.4 The role of the Expanded Programme on Immunisation	126
12.5 Preventive treatment	126
12.5.1 Target groups for preventive treatment	126
12.5.2 Role of isoniazid preventive treatment in HIV-positive individuals	127





INTRODUCTION

HIV-related tuberculosis (TB/HIV) is common in various populations, especially in sub-Saharan Africa and, increasingly, in Asia and South America. Many countries where tuberculosis is common have national tuberculosis control programmes. HIV infection increases the demands on these programmes, which are struggling to cope with the increased tuberculosis case load. The rise in tuberculosis suspects is putting a strain on diagnostic services. Extra-pulmonary and smear-negative pulmonary tuberculosis cases, which are more difficult to diagnose, account for an increased proportion of total cases. There are more adverse drug reactions. There is a higher morbidity and mortality, partly due to other, curable, HIV-related infections. The risk of tuberculosis recurrence is higher.

The essential activities of tuberculosis control are the same even in populations where HIV infection is common. The objectives of a tuberculosis control programme are to decrease morbidity, mortality and transmission of tuberculosis, while avoiding the emergence of drug resistance. The WHO strategy is to provide short-course chemotherapy under direct observation to, at least, all identified smear-positive cases. The provision of short-course chemotherapy for tuberculosis patients is one of the most cost-effective of all health interventions. The aim is to achieve global targets of 85% cure rate and 70% case detection rate. The impact of HIV exposes any weaknesses in tuberculosis control programmes. The HIV epidemic heightens the need to focus on the identification and cure of infectious tuberculosis patients.

This manual is mainly for doctors and other health professionals who work in district hospitals and health centres in high HIV and tuberculosis prevalence countries. At present, the biggest burden of TB/HIV is in sub-Saharan Africa, so this manual mainly deals with sub-Saharan Africa. However, we hope the manual will also be helpful in other parts of the world where the problem of TB/HIV is increasing.

Facilities vary from hospital to hospital. In this manual we assume your hospital has a small laboratory and X-ray service. Even if you do not have these facilities, we hope that the manual will still be useful. Health professionals who care for tuberculosis patients now need to know how to diagnose and treat tuberculosis and other HIV-related diseases. This manual will help you in this task.



The manual fits into a white coat pocket so you can use it on the ward, in the clinic and at home. There is not enough room in a pocket manual for all the possible information you may want to know about TB/HIV. So, at the end of each chapter there are suggestions for further reading. These suggestions include relevant books, background material, reviews and recent articles in journals.

Since English is not the first language of many of the people using this manual, the writing style is deliberately simple. For brevity, the use of the words "he/him/his" stands also for "she/her/hers" where the text could refer to either a man/boy or a woman/girl.

You are welcome to send any comments on the manual to the WHO Global Tuberculosis Programme. We will use your comments to help improve future editions. Many of the references in the manual are to WHO publications. To order copies of WHO publications, you should contact WHO Publications, Distribution and Sales, 1211 Geneva 27, Switzerland.



GLOSSARY

This glossary explains the abbreviations and some of the words used in this book.

acquired resistance	resistance of Mycobacterium tuberculosis to anti-TB drugs in a TB patient who has previously received anti-TB treatment
adherence to treatment	the patient taking the medicines as an addition to other treatment
adjuvant treatment	as an addition to other treatment
AFBs	Acid-Fast Bacilli
agranulocytosis	absence of polymorph white blood cells
AIDS	Acquired ImmunoDeficiency Syndrome
anorexia	loss of appetite for food
ARC	AIDS-Related Complex
atypical mycobacteria	non-tuberculous mycobacteria
bactericidal	kills bacteria
bacteriostatic	stops bacteria from growing
BCG	Bacille Calmette-Guerin
bubo	swollen, pus-containing lymph node
caseation	tissue breakdown by TB bacilli, forming yellow-white, cheese-like material
chemotherapy	treatment with chemical drugs, e.g. anti-TB chemotherapy means treatment with anti-TB drugs
CD4 cells	sub-group of T-lymphocytes carrying CD4 antigens
CMV	CytoMegalovirus
CNS	Central Nervous System
co-infection	infection with different pathogens at the same time, e.g. Mycobacterium tuberculosis and HIV
contacts	people (often family members) close to a TB patient and at risk of infection
counselling	face-to-face communication in which one person (counsellor) helps another (patient/client) to make decisions and act on them
CSF	CerebroSpinal Fluid



dactylitis	inflammation of the fingers
default	patient stopping treatment before completion
desensitisation	way of overcoming hypersensitivity to a drug in a patient by gradual re-exposure to the drug
disseminated	spread throughout the body to many different organs
dormant	sleeping or inactive
DOT	Directly Observed Therapy (supervisor watches patient to ensure the patient takes the tablets)
erythema nodosum	painful, tender, red nodules over the front of the legs
empirical treatment	treatment for a certain condition without exact diagnostic confirmation by tests
EPL	Expanded Programme on Immunisation
extrapulmonary tuberculosis	tuberculosis outside the lungs
exudate	fluid with a high protein content and inflammatory cells in an area of disease
false negative test result	a test result which shows negative, when the true result is in fact positive
FBC	Full Blood Count
fluorochrome stain	shines brightly under ultraviolet light
gibbus	an acute angle in the spine due to vertebral collapse from TB
hilar	at the root of the lung
hilum	the root of the lung
HIV	Human Immunodeficiency Virus
HIV-negative	blood test shows absence of antibodies against HIV
HIV-positive	blood test shows presence of antibodies against HIV
HIV-related TB	TB occurring in somebody infected with HIV
HIV status	whether a person is known to be HIV-positive or HIV-negative
HIV test	blood test for antibodies against HIV
home care	providing care for a patient in his home rather than in hospital
hypersensitivity reaction	type of immunological reaction to even a small amount of a drug or other antigen, e.g. tuberculin

i.m. injection	intramuscular injection
immunosuppressant drugs	drugs which suppress normal immunity
incidence	the number of new cases of a disease in a population in a given time (usually one year)
induration	thickening e.g. of the skin in a tuberculin test
initial resistance	resistance of Mycobacterium tuberculosis to anti-TB drugs in a TB patient who has never before received anti-TB drugs
IUATLD	International Union Against TB and Lung Disease
JVP	Jugular Venous Pressure
KS	Kaposi's Sarcoma
latent	something that is there but not obvious (it can become obvious later)
lesion	an area of disease in the body
LFTs	Liver Function Tests
MAC	Mycobacterium Avium intracellular (one of the atypical mycobacteria)
MCV	Mean Corpuscular Volume
meningism	presence of clinical features suggestive of meningitis, e.g. headache, neck-stiffness, positive Kernig's sign
mutant bacilli	bacilli which suddenly change genetically and become different from the rest of the population
mutation	a sudden genetic change, e.g. which results in a bacillus becoming drug-resistant
NGO	Non-Governmental Organisation
NSAID	Non-Steroidal Anti-Inflammatory Drug
NTP	National Tuberculosis Programme
opportunistic infection	an infection which "takes the opportunity" to cause disease when a person's immune defence is weak
"passive" case finding	detection of TB cases by active testing (sputum smear) of TB suspects
pathogenesis	how a disease arises
PCP	Pneumocystis carinii Pneumonia
phlyctenular conjunctivitis	painful hypersensitivity reaction of the conjunctiva to primary tuberculosis infection, with inflammation and small red spots



T-lymphocytes type of lymphocyte providing cellular immunity

TMP-SMX **Trimethoprim-Sulfamethoxazole**

tubercles small rounded areas of TB disease

tuberculin protein extracted from TB bacilli (PPD)

tuberculoma rounded area of TB disease, usually 1 cm or more wide

UNICEF **United Nations Children's Fund**

WHO **World Health Organization**

window period the gap of about 3 months between the time when a person becomes infected with HIV and the time when the blood test for HIV first shows positive

ZN stain **Ziehl-Neelsen stain**



PGL where the cornea meets the sclera

PPD **Persistent Generalised Lymphadenopathy**

preventive treatment **Purified Protein Derivative (tuberculin)** treatment aimed at preventing disease, e.g. isoniazid for the prevention of TB in certain circumstances

PTB **Pulmonary Tuberculosis**

PTB suspect patient presenting with features which make the health worker think the patient may have PTB, most importantly cough of more than 3 weeks' duration

regimen a drug, or several drugs, given in certain doses for a stated duration

relapse disease starting again after a patient was declared cured

SCC **Short-Course Chemotherapy**

scrofula tuberculous lymph nodes in the neck

sensitivity tests tests of TB bacilli for sensitivity or resistance to anti-TB drugs

seroconversion when a blood test first shows that a person is HIV seropositive, usually about 3 months after HIV infection

seroprevalence the proportion of people testing seropositive (e.g. for HIV) in a population at any one time

slim disease HIV-related chronic diarrhoea and weight loss

spinal block obstruction to normal flow of CSF around the spinal cord

sputum smear negative absence of AFBs on sputum microscopy

sputum smear positive presence of AFBs on sputum microscopy

STD **Sexually Transmitted Disease**

Stevens-Johnson syndrome a characteristic rash with "target lesion" and inflammation of the mucous membranes

syndrome a group of symptoms and signs

TB **Tuberculosis**

TB/HIV TB and HIV co-infection

TB/HIV patient HIV-infected TB patient

TEN **Toxic Epidermal Necrolysis**

thrombocytopenia low platelet count



1 1 TUBERCULOSIS (TB)

1 1 Basic facts about TB

Mycobacterium tuberculosis

TB is a bacterial disease caused by *Mycobacterium tuberculosis* (and occasionally by *Mycobacterium bovis* and *Mycobacterium africanum*). These organisms are also known as tubercle bacilli (because they cause lesions called tubercles) or as acid-fast bacilli (AFB). When examining sputum containing tubercle bacilli stained with certain dyes under the microscope, the bacilli look red. This is because they are acid-fast (they have kept the dye even after washing with acid and alcohol). Tubercle bacilli can remain dormant in tissues and persist for many years.

Transmission of infection

Transmission occurs by airborne spread of infectious droplets. The source of infection is a person with TB of the lung who is coughing. TB of the lung is pulmonary TB (PTB). This person is usually sputum smear-positive (see Chapter 3). Coughing produces tiny infectious droplets (droplet nuclei). One cough can produce 3,000 droplet nuclei. Transmission generally occurs indoors, where droplet nuclei can stay in the air for a long time. Ventilation removes droplet nuclei. Direct sunlight quickly kills tubercle bacilli, but they can survive in the dark for several hours. Two factors determine an individual's risk of exposure: the concentration of droplet nuclei in contaminated air and the length of time he breathes that air.

Risk of infection

An individual's risk of infection depends on the extent of exposure to droplet nuclei and his susceptibility to infection. The risk of infection of a susceptible individual is therefore high with close, prolonged, indoor exposure to a person with sputum smear-positive PTB. The risk of transmission of infection from a person with sputum smear-negative PTB is low, and with extra-pulmonary TB is even lower.

Risk of progression of infection to disease.

Once infected with *M. tuberculosis*, a person stays infected for many years, probably for life. The vast majority (90%) of people without HIV



infection who are infected' with *M. tuberculosis* do not develop tuberculosis disease. In these healthy, asymptomatic, but infected individuals, the only evidence of infection may be a positive tuberculin skin test.

Infected persons can develop tuberculosis disease at any time. The chance of developing disease is greatest shortly after infection and then steadily lessens as time goes by. Various physical or emotional stresses may trigger progression of infection to disease. The most important trigger is weakening of immune resistance, especially by HIV infection. Disease can affect most tissues and organs, but especially the lungs.

Natural history of untreated TB

Without treatment, after 5 years, 50% of pulmonary TB patients will be dead, 25% will be healthy (self-cured by strong immune defence) and 25% will remain ill with chronic, infectious TB.

Epidemiology

M. tuberculosis infects a third of the world's population. Worldwide in 1995 there were about 9 million new cases of TB with 3 million deaths. These deaths comprise 25% of all avoidable deaths in developing countries. 95% of TB cases and 98% of TB deaths are in developing countries. 75% of TB cases in developing countries are in the economically productive age group (15-50 years).

1 2 Pathogenesis of TB

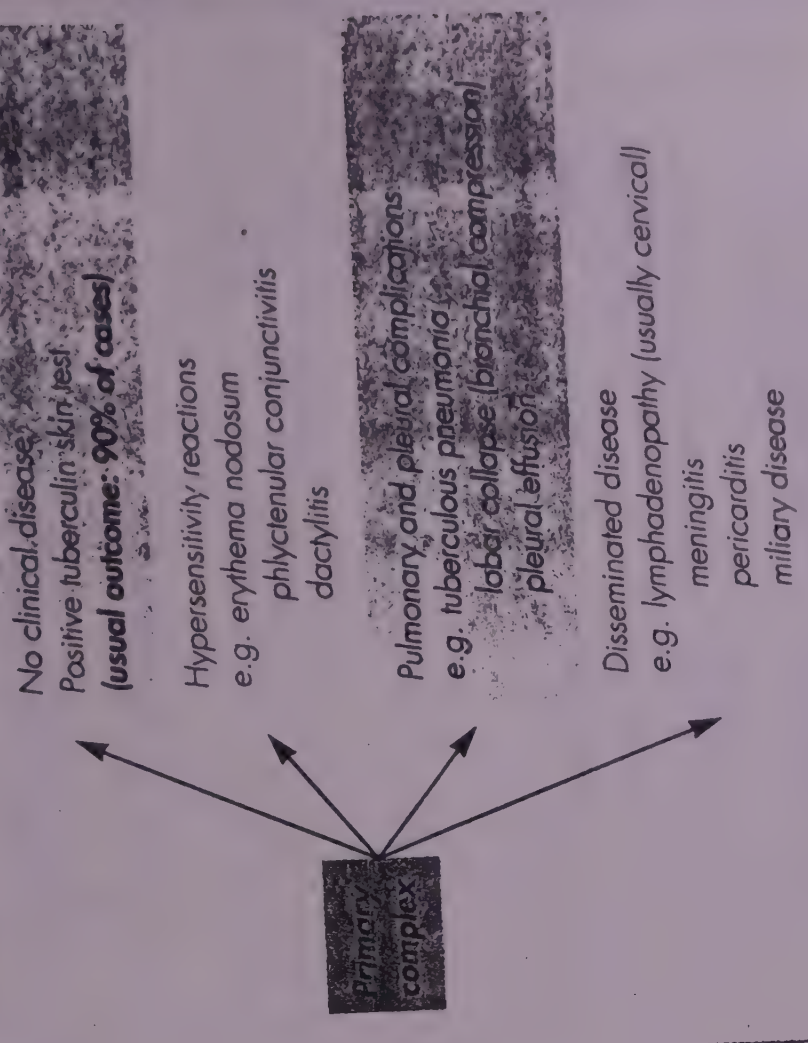
Primary infection

Primary infection occurs on first exposure to tubercle bacilli. Inhaled droplet nuclei are so small that they avoid the mucociliary defences of the bronchi and lodge in the terminal alveoli of the lungs. Infection begins with multiplication of tubercle bacilli in the lungs. This is the Ghon focus. Lymphatics drain the bacilli to the hilar lymph nodes. The Ghon focus and related hilar lymphadenopathy form the primary complex. Bacilli may spread in the blood from the primary complex throughout the body. The immune response (delayed hypersensitivity and cellular immunity) develops about 4-6 weeks after the primary infection. The size of the infecting dose of bacilli and the strength of the immune response determine what happens next. In most cases, the immune response stops the multiplication of bacilli. However, a few dormant bacilli may persist. A positive tuberculin skin test would be the only evidence of infection. The immune



response in a few cases is not strong enough to prevent multiplication of bacilli, and disease occurs within a few months.

Outcome of primary infection



PRACTICAL POINT

Following primary infection, rapid progression to intra-thoracic disease is more common in children than in adults. Chest X-ray may show intrathoracic lymphadenopathy and lung infiltrates.

Post-primary TB

Post-primary TB occurs after a latent period of months or years after primary infection. It may occur either by reactivation or by reinfection. Reactivation means that dormant bacilli persisting in tissues for months or years after primary infection start to multiply. This may be in response to a trigger, such as weakening of the immune system by HIV infection. Reinfection means a repeat infection in a person who has already



previously had a primary infection.

Postprimary TB usually affects the lungs but can involve any part of the body. The characteristic features of postprimary PTB are the following: extensive lung destruction with cavitation; positive sputum smear; upper lobe involvement; usually no intrathoracic lymphadenopathy.

Post-PRIMARY TB

PULMONARY TB

e.g. cavities
upper lobe infiltrates
fibrosis
progressive pneumonia
endobronchial

EXTRA-PULMONARY TB

COMMON

Pleural effusion
Lymphadenopathy (usually cervical)
Central nervous system (meningitis, cerebral tuberculoma)
Pericarditis (effusion/constrictive)
Gastro-intestinal (ileocaecal, peritoneal)
Spine, other bone and joint

LESS COMMON

Empyema
Male genital tract (epididymitis, orchitis)
Female genital tract (ubo-ovarian, endometrium)
Kidney
Adrenal gland
Skin (lupus vulgaris, tuberculids, milium)
Lupus vulgaris, tuberculids, milium)

PRACTICAL POINT

Post-primary infection with pulmonary disease usually occurs in adults, with positive sputum smears.

1 2 HUMAN IMMUNODEFICIENCY VIRUS (HIV)

1 2 1 Introduction: HIV and AIDS

Since the first description of AIDS in 1981, researchers have identified 2 serotypes of HIV, the cause of AIDS. HIV-1 is the predominant serotype worldwide. HIV-2 occurs most commonly in West Africa. They both cause AIDS and the routes of transmission are the same. However, HIV-2 transmission is slightly less easy and HIV-2 may cause slower progression to AIDS.

1 2 2 HIV/AIDS epidemiology

In 1995 worldwide there were about 17 million HIV-infected adults. An estimated 6 million adult and paediatric AIDS cases have occurred since the HIV pandemic began. Most of these cases of HIV and AIDS have been in sub-Saharan Africa and the Americas. There are now growing numbers in South East Asia. In some sub-Saharan African countries, HIV seroprevalence in the general population aged over 15 years is as high as 20%.

1 2 3 HIV transmission

The main modes of transmission of HIV are through sexual intercourse, blood and from mother to infant. Worldwide the most important route of transmission is through sexual intercourse. In most low-income countries equal numbers of men and women are HIV-infected. Other sexually transmitted diseases (especially those causing genital ulcers) increase the risk of HIV transmission. Bloodborne HIV transmission occurs through contaminated blood transfusion, injections with contaminated needles and syringes, and the use of non-sterile skin-piercing instruments. About one third of children born to HIV-infected mothers are also HIV-infected. There is a small risk of HIV transmission through breastfeeding. However, in many low-income countries breastfeeding is still a safer alternative to bottle-feeding.

There is no evidence that HIV transmission occurs through everyday contact, hugging or kissing, food or drink, or bites of mosquitoes or other insects.



Transmission to patients

Patients may potentially be at risk of HIV infection from HIV-positive staff and HIV-positive other patients. Known HIV-positive staff should not perform invasive procedures (surgery, invasive diagnostic or therapeutic procedures) on patients. Cross-infection between patients can occur from contaminated medical, surgical or dental equipment. It is vital to follow recommended sterilisation procedures. When and where possible, reducing injections helps to decrease the risk of cross-infection.

Transmission to staff

Most HIV-positive health workers acquire HIV infection outside the workplace by sexual transmission from an HIV-positive partner/spouse. The risk of transmission of HIV from patients to staff is small if staff observe standard infection control procedures. In health units, HIV transmission is less common than hepatitis B transmission. Less than 0.5% of health workers exposed by a needle-slick injury to the blood of an HIV-positive patient have acquired HIV infection. Handle all "sharps" carefully. If you have a needle-slick injury, squeeze the wound to encourage blood flow and wash well with soap and water. In high HIV prevalence areas, assume that all blood and body fluids are potentially infectious. The table gives some guidance on prevention of transmission to health workers.

PRECAUTIONS FOR PREVENTION OF TRANSMISSION OF HIV

EXPOSURE TO RISK	PRECAUTIONS FOR PREVENTION OF TRANSMISSION OF HIV
needle puncture	wear gloves use a closed vacuum system if available discard needle and syringe into sharps box discard gloves and swabs into leak-proof plastic bag for incineration label blood bottle and request form "inoculation risk"
invasive procedure, surgery, delivery of a baby	wear gloves and apron protect your eyes (goggles or protective goggles) discard sharps into sharps box
spilled blood or other body fluids	clear up as soon as possible using available disinfectant (e.g. glutaraldehyde, phenol, sodium hypochlorite)
resuscitation	avoid mouth-to-mouth resuscitation (use bag and mask)

wear gloves and apron
dispose into leak-proof plastic bags
wash laundry at high temperatures or with appropriate chemical disinfectant

1 2 5 Immunopathogenesis of HIV infection

The helper subset of T-lymphocytes is central to cell-mediated immunity. These cells carry the CD4 antigen on their surface (CD4+ lymphocytes). HIV recognises the CD4 antigen, and enters and infects CD4+ lymphocytes. The result is killing of many CD4+ lymphocytes (progressive decrease in CD4+ lymphocyte count) and poor function of the survivors. Progressive HIV infection therefore causes progressive decline in immunity.

1 2 6 Natural history of HIV infection

Acute HIV infection

Most people infected with HIV do not know that they have become infected. HIV infected persons develop antibodies to HIV antigens usually 6 weeks, but up to 3 months, after infection. This "seroconversion" is when a person recently infected with HIV first tests sero-positive for HIV antibodies. Some people have a "glandular fever"-like illness (fever, rash, arthralgia and lymphadenopathy) at the time of seroconversion. Occasionally acute neurological syndromes may occur which are often self-limiting. These include aseptic meningitis, peripheral neuropathy, encephalitis and myelitis. A severe seroconversion illness may predict a worse long term outcome.

Asymptomatic HIV infection

In adults, there is a long, variable, latent period from HIV infection to the onset of HIV-related disease and AIDS. A person infected with HIV may be asymptomatic for up to 10 years or more. The vast majority of HIV-infected children are infected in the perinatal period. The period of asymptomatic infection is shorter in children than in adults. A few infants become ill in the first few weeks of life. Most children start to become ill before 2 years of age. A few children remain well for several years.

Progression from HIV infection to HIV-related disease and AIDS

Almost all (if not all) HIV infected people will ultimately develop HIV-related



disease and AIDS. Some HIV-infected individuals progress more quickly than others to HIV-related disease and AIDS. The rate of progression depends on virus and host characteristics. Virus characteristics include serotype and strain: HIV-1 and certain HIV strains may cause faster progression. Host characteristics which may cause faster progression include age less than 5 years, age more than 40 years, concurrent infections, and possibly genetic factors.

Persistent generalised lymphadenopathy (PGL)

This occurs in about one third of otherwise healthy HIV-infected people. The enlarged lymph nodes are persistent, generalised, symmetrical, and nontender.

Early immunosuppression

As HIV infection progresses and immunity declines, patients become more susceptible to infections. These include tuberculosis, septicæmia, pneumonia, and recurrent fungal infections of the skin and oropharynx. Patients may develop constitutional symptoms (unexplained fever and weight loss), sometimes known as "AIDS-related complex" (ARC). Some patients develop chronic diarrhoea with weight loss, often known as "slim disease".

Late immunosuppression

Any infection that can occur with early immunosuppression can also occur with late immunosuppression. In addition, certain specific HIV-related diseases occur predominantly with severe immunosuppression. These include certain opportunistic infections (e.g. cryptococcal meningitis) and certain tumours (e.g. Kaposi's sarcoma). At this late stage, the patient usually dies in less than 1-2 years. This late stage is sometimes known as "full-blown AIDS".

PRACTICAL POINT

Tuberculosis can occur at any point in the course of progression of HIV infection.

1 2 7 AIDS

AIDS is a term with an official definition used for epidemiological surveillance. This means that systematic reporting of AIDS cases is useful

in helping to monitor the HIV pandemic and to plan public health responses. The term AIDS is not useful for the clinical care of individual patients. In managing patients with HIV-related disease, the aim is to identify and treat whichever HIV-related diseases are present.

PRACTICAL POINT

The term AIDS is used for epidemiological surveillance, not for clinical care.

1 2 8 WHO case definitions for AIDS surveillance

ADULTS AND ADOLESCENTS

WHO has recommended AIDS case definitions for use in adults and adolescents in countries with limited clinical and laboratory diagnostic facilities. The recommended case definition depends on whether HIV testing is available. One case definition is for use where HIV testing is not available. The other case definition is for use where HIV testing is available.

WHO case definition for AIDS surveillance where HIV testing is not available.

The case definition for AIDS is fulfilled in the presence of at least 2 major signs and at least 1 minor sign.

Major signs

- weight loss > 10% of body weight
- chronic diarrhoea for more than 1 month
- prolonged fever for more than 1 month

Minor signs

- persistent cough for more than 1 month
- generalised pruritic dermatitis
- history of herpes zoster
- oropharyngeal candidiasis
- chronic progressive or disseminated herpes simplex infection
- generalised lymphadenopathy

- For patients with tuberculosis, persistent cough for more than 1 month should not be considered as a minor sign.

The presence of either generalised Kaposi's sarcoma or cryptococcal meningitis is sufficient for the case definition of AIDS.

The advantages of this case definition are that it is simple to use and inexpensive. The disadvantages are its relatively low sensitivity and specificity. For example, HIV-negative tuberculosis cases could be counted as AIDS cases because of their similarity in clinical presentation.

WHO case definition for AIDS surveillance where HIV testing is available

The case definition for AIDS is fulfilled in the presence of a positive HIV test and 1 or more of the following conditions:

- weight loss > 10% body weight, or cachexia, with diarrhoea or fever, or both, for at least 1 month, not known to be due to a condition unrelated to HIV infection
- cryptococcal meningitis
- tuberculosis (pulmonary or extrapulmonary)
- Kaposi's sarcoma
- neurological impairment which prevents independent daily activities, not known to be due to a condition unrelated to HIV infection
- oesophageal candidiasis
- life-threatening, or recurrent episodes of, pneumonia
- invasive cervical cancer

An advantage of this case definition is that it has a higher specificity. A disadvantage is that it requires the availability of HIV serological testing, which may be logistically difficult and costly.

CHILDREN

WHO case definition for AIDS surveillance where HIV testing is not available

The case definition for AIDS is fulfilled in the presence of at least 2 major signs and 2 minor signs (if no other known cause of immunosuppression).

Major signs

- weight loss or abnormally slow growth
- chronic diarrhoea (> 1 month)
- prolonged fever (> 1 month)



Minor signs

- generalised lymph node enlargement
- oropharyngeal candidiasis
- recurrent common infections, e.g. ear infections, pharyngitis
- persistent cough
- generalised rash

Confirmed HIV infection in the mother counts as a minor criterion. This definition is not very specific.

WHO case definition for AIDS surveillance where HIV testing is available

This case definition is complex and depends on advanced clinical and laboratory diagnostic facilities. The applicability of this case definition is therefore limited and is beyond the scope of this manual. Those interested should see the suggestions for further reading at the end of the chapter.

1 3 HIV-RELATED TB

1 3 1 Epidemiology of co-infection of HIV and M. tuberculosis

In 1995, about one third of the 15 million HIV-infected people worldwide were also co-infected with *M. tuberculosis*. 70% of co-infected people live in sub-Saharan Africa, 20% in Asia and 8% in Latin America and the Caribbean.

1 3 2 HIV infection and risk of TB

HIV increases a person's susceptibility to infection with *M. tuberculosis*. In a person infected with *M. tuberculosis*, HIV is a potent cause of progression of tuberculosis infection to disease.

Consider an individual infected with *M. tuberculosis*. The table shows the effect of HIV infection on his lifetime risk of developing TB.

HIV STATUS	LIFETIME RISK OF DEVELOPING TB
negative	5-10 %
positive	50 %



PRACTICAL POINT

HIV is the most powerful factor known to increase the risk of TB.

133 Consequence of HIV/M. tuberculosis co-infection

Compared to an individual who is not infected with HIV, an individual infected with HIV has a 10 times increased risk of developing TB. TB notifications have increased in populations where both HIV infection and M. tuberculosis infection are common, e.g. some parts of sub-Saharan Africa have seen a tripling in the number of notifications over the past decade. HIV seroprevalence in these TB patients is upto 70%. In sub-Saharan Africa, one third or more of HIV-infected people may develop TB.

134 Impact of HIV on TB control

The principles of TB control are the same even when there are many HIV/TB patients. However, in populations where HIV/TB is common, health services struggle to cope with the large and rising numbers of TB patients.

The consequences include the following:

- over-diagnosis of sputum smear-negative PTB
- under-diagnosis of sputum smear-positive PTB
- inadequate supervision of anti-TB chemotherapy
- low cure rates
- high mortality rates during treatment
- high default rates because of adverse drug reactions
- high rates of TB recurrence
- increased emergence of drug resistance

135 Patterns of HIV-related TB

As HIV infection progresses, CD4+ lymphocytes decline in number and function. The immune system is less able to prevent the growth and local spread of M. tuberculosis. Disseminated and extra-pulmonary disease is more common.

Pulmonary TB

Even in HIV-infected patients, PTB is still the commonest form of TB.

The presentation depends on the degree of immunosuppression. The table below shows how the clinical picture, sputum smear result and chest X-ray appearance often differ in early and late HIV infection.

How PTB differs in early and late HIV infection			
features of PTB	Stage of HIV infection		
	early	late	
clinical picture	often resembles post-primary PTB	often resembles primary PTB	
sputum smear result	often positive	often negative	
chest X-ray appearance	often cavities	often infiltrates with no cavities	

Extra-pulmonary TB

The commonest forms are the following: lymphadenopathy, pleural effusion, pericardial disease, miliary disease, meningitis.

HIV-related TB in children

As in adults, the natural history of TB in a child infected with HIV depends on the stage of HIV disease. Early in HIV infection, when immunity is good, the signs of TB are similar to those in a child without HIV infection. As HIV infection progresses and immunity declines, dissemination of TB becomes more common. Tuberculous meningitis, miliary tuberculosis, and widespread tuberculous lymphadenopathy occur.

136 Impact of TB on HIV

In an individual infected with HIV, the presence of other infections, including TB, may allow HIV to multiply more quickly. This may result in more rapid progression of HIV infection and AIDS.

SUGGESTIONS FOR FURTHER READING

TUBERCULOSIS

Crofton J, Horne N and Miller F. Clinical Tuberculosis. The MacMillan Press Limited. 1992.

Davies PDO. Clinical Tuberculosis. Chapman and Hall Medical. 1994.
International Union Against Tuberculosis and Lung Disease. Tuberculosis Guide For Low Income Countries. pmi Verlagsgruppe. 3rd edition.

Frankfurt, 1994.
Raviglione MC, Snider D, Kochi A. Global epidemiology of tuberculosis. Morbidity and mortality of a worldwide epidemic. JAMA 1995; 273: 220-226.

HIV/AIDS

WHO Global Programme on AIDS. AIDS in Africa: A manual for physicians. Geneva, 1992.
WHO Global Programme on AIDS. Preventing HIV transmission in health facilities. Geneva, 1995.
WHO. AIDS: images of the epidemic. Geneva, 1994.
Mertens TE, Burton A, Stoneburner R, et al. Global estimates and epidemiology of HIV infections and AIDS. AIDS 1994, 8(suppl 1): S361-S372.

AIDS case definitions for surveillance

Acquired Immunodeficiency Syndrome (AIDS). WHO/CDC case definition for AIDS. Wkly Epidem Rec 1986; 61: 69-73. (WHO clinical case definitions for AIDS in children where HIV testing is not available).
Acquired Immunodeficiency Syndrome (AIDS). 1987 revision of CDC/WHO case definition for AIDS. Wkly Epidem Rec 1988; 63: 1-7. (WHO case definition for AIDS in children where HIV testing is available).
WHO case definitions for AIDS surveillance in adults and adolescents. Wkly Epidem Rec 1994; 69: 273-275. (WHO case definitions for AIDS in adults).

HIV-RELATED TUBERCULOSIS

Narain JP, Raviglione MC, Kochi A. HIV-associated tuberculosis in developing countries: epidemiology and strategies for prevention. Tubercle and lung Disease 1992; 73: 311-321.



2 1 INTRODUCTION

WHO has declared that TB is a global emergency, because TB is out of control in many parts of the world. The following are the main reasons why TB is out of control:

- a) governments in many parts of the world have neglected the disease;
- b) inadequate TB control programmes have led to an increased burden of disease (inadequately treated TB patients live longer with chronic disease and infect other people) and the emergence of drug-resistant TB;
- c) high rates of population growth have contributed to an increased number of TB cases;
- d) the HIV epidemic has led to an enormous increase in the number of TB cases, in places where HIV and TB are both common.

WHO has developed a new framework of strategy and policy for TB control in response to this global emergency. This strategy and policy is unchanged in the face of the epidemic of TB/HIV co-infection. It is vital for successful TB control for health care workers to treat TB patients within this framework in a National TB Programme (NTP).

2 2 COMPONENTS OF TB CONTROL FRAMEWORK

The framework consists of the following:

- 1. Overall objectives of TB control.
- 2. Strategy for TB control.
- 3. Targets for TB control.
- 4. TB control policy package.
- 5. Key operations of a national TB programme.
- 6. Indicators to measure progress in TB control.

2 2 1 Overall objectives of TB control

To reduce mortality, morbidity and disease transmission (while avoiding the development of drug resistance).



2 2 2 Strategy for TB control

To provide short-course chemotherapy under direct observation to, at least, all identified smear-positive TB cases (the sources of infection).

2 2 3 Targets for TB control

- a) To cure 85% of new detected cases of sputum smear-positive PTB. A national TB programme which achieves at least an 85% cure rate in patients with sputum smear-positive PTB has the following impact on TB:
 - i) TB prevalence and the rate of TB transmission both decrease immediately;
 - ii) TB incidence decreases gradually;
 - iii) there is less acquired drug resistance (which makes future treatment of TB easier and more affordable).
- b) To detect 70% of existing cases of sputum smear-positive PTB. It is important to expand case-finding only when a national TB programme has achieved a high cure rate. A national TB programme which has a low cure rate makes the TB problem worse:
 - i) there are more cases of sputum smear-positive PTB (treatment failure);
 - ii) transmission of acquired drug-resistance increases.A treatable epidemic becomes an untreatable epidemic.

AN EFFECTIVE NTP HAS A HIGH CURE RATE AND A LOW LEVEL OF ACQUIRED DRUG RESISTANCE.

In the presence of a high cure rate, increased case detection of sputum smear-positive PTB cases will decrease TB transmission.

2 2 4 TB control policy package

The success of the WHO strategy depends on the implementation of a 5-point package:

- i) government commitment to a national TB programme;
- ii) case detection through "passive" case-finding (sputum smear microscopy for PTB suspects);
- iii) short-course chemotherapy for all smear-positive PTB cases (under direct observation for, at least, the initial phase of treatment);
- iv) regular, uninterrupted supply of all essential anti-TB drugs;
- v) monitoring system for programme supervision and evaluation.

2 2 5 Key features of a national TB programme (NTP)

- i) NTP has a central unit.
- ii) NTP manual.
- iii) A recording and reporting system using standardised registers.
- iv) A training programme covering all aspects of the policy package.
- v) Microscopy services nationwide.
- vi) Treatment services integrated with existing health services, with priority for supervised short-course chemotherapy.
- vii) Regular supply of drugs and diagnostic materials.
- viii) Plan of supervision.
- ix) A project development plan, with details of budget, sources of funding and responsibilities.

2 2 6 Indicators to measure NTP progress in TB control.

- i) NTP manual (reflects government commitment).
- ii) The number of administrative areas in the country which are implementing the new TB control strategy.
- iii) The cure rate.
- iv) The case detection rate.

2 3 DIRECTLY OBSERVED THERAPY

What is directly observed therapy?

To ensure the treatment cures the patient, we have to ensure patient adherence to the treatment. Patient adherence to short-course chemotherapy means the patient takes every dose of the recommended treatment regimen. It is difficult for a patient to adhere to anti-TB treatment for 8 months. It is difficult to predict which TB patients will adhere to self-administered treatment. Therefore one certain way to ensure patient adherence to treatment is direct observation of therapy (DOT). This means that a supervisor watches the patient swallowing his tablets. The NTP trains and monitors the supervisors.

Directly observed therapy as close to the patient's home as possible

A TB patient is unlikely to adhere to treatment if he has far to go for treatment. One of the aims of a TB programme is to organise TB services so that the patient has TB treatment as close to home as possible. A TB

programme brings TB treatment to TB patients wherever they live. Many TB patients live close to a health facility (e.g. health centre, district hospital). For these patients, the supervisor of directly observed therapy will therefore be one of the health staff in the health facility. Some TB patients live far away from a health facility. For these patients, the supervisor will be a trained local community member or health outreach worker. Some areas have HIV/AIDS community care schemes. The HIV/AIDS home care providers with suitable training and supervision can administer directly observed therapy.

Integration of TB treatment services with general health services

In the past, some TB programmes have relied only on special TB hospitals and clinics, separate from the general health services. The big problem with that system is that many TB patients live far from TB hospitals and clinics. One reason why TB is out of control in many countries is because TB patients do not have access to TB diagnosis and treatment services. A successful NTP brings TB diagnosis and treatment services to the TB patients. This is why TB treatment services are integrated with existing health services.

SUGGESTIONS FOR FURTHER READING

World Health Organization. *TB - A Global Emergency. WHO report on the TB epidemic, 1994.* Geneva: WHO, 1994.

World Health Organization. *Stop TB at the source. WHO report on the TB epidemic, 1995.* Geneva: WHO, 1995.

World Health Organization. *Groups at risk. WHO report on the tuberculosis epidemic 1996.* Geneva: WHO, 1996.

World Health Organization. *Framework for effective tuberculosis control. WHO Tuberculosis Programme, 1994.* Geneva: WHO, 1994.

World Health Organization. *Treatment of Tuberculosis: Guidelines for national programmes.* Geneva: WHO, 1993.

International Union Against Tuberculosis and Lung Disease. *Tuberculosis guide for low income countries.* pmi Verlagsgruppe. 3rd edition. Frankfurt, 1994.

World Health Organization. *Tuberculosis Control Workshop Report, Geneva, October 1995, and Revision of "Treatment of Tuberculosis: Guidelines for National Programme".* Geneva: WHO, 1996.



3 1 PULMONARY TB

3 1 1 Diagnostic approach

The highest priority for TB control is the identification and cure of the infectious cases, i.e. patients with sputum smear-positive PTB. Therefore all patients (regardless of HIV status) with clinical features suspicious of PTB must submit sputum for diagnostic sputum smear microscopy. Most TB suspects are ambulatory. The diagnosis of PTB is therefore usually on an out-patient basis. A few TB suspects are severely ill and/or bed-bound and therefore need investigation as in-patients.

Clinical screening by assessment of symptoms identifies PTB suspects among patients attending health facilities. The most cost-effective method of screening PTB suspects in high-prevalence countries is by sputum smear microscopy. When a suspect has a positive sputum smear, he has sputum smear-positive PTB. Register him with the district TB officer and start treatment. In most cases, a chest X-ray is unnecessary.

In populations with a high TB prevalence, the tuberculin skin test is of little value in the diagnosis of TB in adults. A positive tuberculin skin test does not by itself distinguish *M. tuberculosis* infection from tuberculosis disease. Previous exposure to environmental mycobacteria may also result in a false-positive test result. Conversely, the tuberculin skin test result may be negative, even when the patient does have TB. Conditions often associated with a false-negative tuberculin skin test include HIV infection, severe malnutrition and military TB.

3 1 2 Clinical features

Symptoms

The most important symptoms in the diagnosis of PTB are the following:

cough > 3 weeks

sputum production

weight loss



Over 90% of patients with sputum smear-positive PTB develop a cough soon after disease onset. However, cough is not specific to PTB. Cough is common in smokers and in patients with acute upper or lower respiratory tract infection. Most acute respiratory infections resolve within 3 weeks. Therefore a patient with a cough for more than 3 weeks is a PTB suspect and must submit sputums for diagnostic microscopy.

Patients with PTB may also have other symptoms. These may be respiratory or constitutional (general or systemic).

Respiratory: haemoptysis, chest pain, breathlessness

Constitutional: fever/night sweats, tiredness, loss of appetite

Weight loss and fever are more common in HIV-positive PTB patients than in those who are HIV-negative. Conversely, cough and haemoptysis are less common in HIV-positive PTB patients than in those who are HIV-negative. This is probably because there is less cavitation, inflammation and endobronchial irritation in HIV positive patients.

Physical signs

The physical signs in patients with PTB are non-specific. They do not help to distinguish PTB from other chest diseases.

PRACTICAL POINT

PTB suspects (patients with suggestive symptoms) must submit sputums for sputum smear microscopy.

3.1.3 Diagnostic sputum smear microscopy

Collection of sputum samples

A PTB suspect should submit 3 sputum samples for microscopy. The chances of finding tubercle bacilli are greater with 3 sputum samples than with 2 samples or 1 sample. Secretions build up in the airways overnight. So an early morning sputum sample is more likely than a sample later in the day to contain tubercle bacilli. It may be difficult for an out-patient to provide 3 early morning sputum samples. Therefore in practice an out-patient usually provides sputum samples as follows:

day 1 . . . sample 1 . . . Patient provides an "on the spot" sample under supervision when he presents to the health facility. Give the patient a sputum container to take home for an early morning sample the following morning.

day 2 . . . sample 2 . . . Patient brings an early morning sample.

. sample 3 . . . Patient provides another "on the spot" sample under supervision.

If a patient can't produce a sputum sample, a nurse or physiotherapist may help him to give a good cough and bring up some sputum. An in-patient can provide 3 early morning sputum samples under supervision in hospital.

Terminology

Mycobacteria are "acid- and alcohol-fast bacilli" (AAFB), often shortened to "acid-fast bacilli" (AFB). The waxy coat of mycobacteria retains an oiline dye (e.g. carbol fuchsin) even after decolourisation with acid and alcohol.

Ziehl-Neelsen (Z-N) stain

This simple stain detects AFB. This is how to perform the Z-N stain:

- fix the smear on the slide ▼
- cover the fixed smear with carbol fuchsin for 3 minutes ▼
- heat, rinse with tap water, and decolourise with acid-alcohol for 3-5 seconds ▼
- counter-stain with methylene blue for 30 seconds ▼
- rinse again with tap water ▼
- observe under the microscope (use the oil immersion lens (x100) and x6 or x8 eye-piece lens) The bacilli appear as red, beaded rods, 2-4 µm long and 0.2-0.5 µm wide.

Fluorochrome stain

This is a different stain for tubercle bacilli. A special fluorescent

microscope is necessary. The fluorochrome stain is phenolic auramine or auramine-rhodamine. After acid-alcohol decolourisation and a methylene blue counterstain, the bacilli fluoresce bright yellow against a dark background. The advantage of this method is that it is possible to scan smears quickly under low magnification. It is important to re-check fluorochrome stain positive smears using the Z-N stain.

Slide reporting

The number of bacilli seen in a smear reflects disease severity and patient infectivity. Therefore it is important to record the number of bacilli seen on each smear. The table below shows the standard method of reporting.

NUMBER OF BACILLI SEEN IN A SMEAR		RESULT REPORTED
no. AFB	per 100 oil-immersion fields	0
1-9 AFB	per 100 oil immersion fields	scanty
10-99 AFB	per 100 oil immersion fields	+
1-10 AFB	per oil immersion field	++
10-100 AFB	per oil immersion field	+++

The laboratory technician must examine all 3 sputum samples from each TB suspect. He must record the result of each sputum sample with the laboratory reference number in the laboratory register and on the sputum request form.

Sensitivity of sputum smear microscopy

Sputum smear microscopy for tubercle bacilli is positive when there are at least 10,000 organisms present per 1 ml of sputum.

Sputum microscopy in HIV infection

Sputum smear positivity rates in TB/HIV patients depend on the degree of immunocompromise, as shown below.

DEGREE OF IMMUNOCOMPROMISE	LIKELIHOOD OF POSITIVE SPUTUM SMEAR
mild	similar to HIV-negative patient
severe	decreased (decreased inflammation in lungs)

False positive results of sputum smear microscopy

A false positive result means that the sputum smear result is positive even though the patient does **not** really have sputum smear-positive PTB. This may arise because of the following: red stain retained by scratches on the slide;

ion of the slide or smear by environmental mycobacteria, that are acid-fast (e.g. food particles, precipitates, other micro-organisms).

False negative results of sputum smear microscopy

A false negative result means that the sputum smear result is negative even though the patient **really does have** sputum smear-positive PTB. This may arise because of problems in collecting, processing, or interpreting sputum smears, or because of administrative errors.

PRACTICAL POINT

If a sputum smear result is unexpectedly negative (e.g. in a patient with upper lobe cavities on chest X-ray), think of the possibility of a false negative result and repeat the sputum microscopy.

Causes of false negative results of sputum smear microscopy

TYPE OF PROBLEM	EXAMPLE
sputum collection	patient provides inadequate sample inappropriate sputum container used sputum stored too long before smear microscopy
sputum processing	faulty sampling of sample for smear faulty smear preparation and staining
sputum smear interpretation	inadequate time spent examining smear inadequate attention to smear (poor motivation)
administrative errors	misidentification of patient incorrect labelling of sample mistakes in documentation

3 1 4 Differential diagnosis of pulmonary TB

PRACTICAL POINT

A PTB suspect with 3 negative sputum smears may not have PTB at all. Reassess the patient in case he has a condition mistaken for PTB.



The table shows the differential diagnosis of PTB.

Differential Diagnosis	Pointers to the correct Diagnosis
congestive cardiac failure	symptoms of heart failure
left ventricular failure	(dyspnoea, orthopnoea, paroxysmal nocturnal dyspnoea, haemoptysis, oedema, epigastric discomfort from hepatic congestion) signs of heart failure
asthma	intermittent symptoms, generalised expiratory wheezes
chronic obstructive airways disease	risk factor (smoking), chronic symptoms, prominent dyspnoea, generalised wheezes
bronchiectasis	large amounts of purulent sputum
bronchial carcinoma	risk factor (smoking)
other infections, e.g. bacterial pneumonia	response to antibiotic
lung abscess	abscess with fluid level on chest X-ray
Pneumocystis carinii	dyspnoea prominent

PRACTICAL POINT

If a patient is breathless, has continuing haemoptyses, and has negative sputum smears, listen carefully for a low-pitched, rumbling, mid-diastolic murmur in case he has mitral stenosis with pulmonary oedema.

3.1.5 Chest X-rays in diagnosis

INDICATIONS FOR CHEST X-RAY

Positive sputum smear

The first screening test for PTB suspects is sputum smear microscopy. In most cases of sputum smear-positive PTB a chest X-ray is unnecessary. In those few cases of sputum smear-positive PTB when a chest X-ray is necessary, the indications are as follows:

- suspected complications in the breathless patient, needing specific treatment, e.g. pneumothorax, (pericardial effusion or pleural effusion - positive sputum smear is rare);
- frequent or severe haemoptysis (to exclude bronchiectasis or aspergilloma);
- only 1 sputum smear positive out of 3 (in this case, an abnormal chest X-ray is a necessary additional criterion for the diagnosis of sputum smear-positive PTB).

Negative sputum smears

Re-assess the patient who continues to cough despite a course of broad-spectrum antibiotic, and who has had 3 negative sputum smears. It is often worthwhile repeating the sputum smears after 2 weeks. If you still suspect TB despite negative sputum smears, the patient needs a chest X-ray.

3.1.6 Patterns of disease in PTB

PRACTICAL POINT

No chest X-ray pattern is absolutely typical of PTB.

The table shows the so-called "classical" and "atypical" patterns. The classical pattern is more common in HIV-negative patients. The atypical pattern is more common in HIV positive-patients.

CLASSICAL PATTERN	ATYPICAL PATTERN
upper lobe infiltrates	interstitial infiltrates
bilateral infiltrates	(especially lower zones)
cavitation	no cavitation
pulmonary fibrosis and shrinkage	no abnormalities

PRACTICAL POINT

Chest X-ray changes in TB/HIV patients reflect the degree of immunocompromise. In mild immunocompromise, the appearance is often classical (with cavitation and upper lobe infiltrates). In severe immunocompromise, the appearance is often atypical.



The chest X-ray findings associated with PTB are non-specific. Diseases other than PTB can cause both the "classical" and the "atypical" chest X-ray findings.

PRACTICAL POINT

The vast majority of patients (over 90%) with cavitary PTB are sputum smear-positive. Therefore, a patient with cavities on chest X-ray and repeated negative sputum smears probably has a disease other than PTB.

The table shows the differential diagnosis of chest X-ray findings often associated with PTB.

CHEST X-RAY FINDING	DIFFERENTIAL DIAGNOSIS
cavitation	infections some bacterial pneumonias lung abscess some fungal infections non-infectious disease bronchial carcinoma connective tissue disease occupational lung disease
unilateral infiltration	pneumonia bronchial carcinoma
bilateral infiltration	pneumonia connective tissue disease occupational lung disease sarcoidosis
mediastinal lymphadenopathy	lymphoma bronchial carcinoma sarcoidosis



This is a common, and often difficult, diagnostic problem. Several diseases in HIV-positive individuals may present in a similar way with cough, fever, sometimes chest signs, and chest X-ray shadowing. In each case it is important to make a careful clinical assessment and send sputum samples for AFBs if the patient has had cough for 3 weeks or more.

Acute bacterial pneumonia

This is common in HIV-positive patients. The shorter history usually differentiates pneumonia from PTB. The most common pathogen is *Streptococcus pneumoniae*. Regardless of HIV status, acute bacterial pneumonia usually responds well to standard treatment with penicillin, co-trimoxazole or ampicillin.

PRACTICAL POINT

If pneumonia fails to respond to standard antibiotics, consider other pathogens, e.g. *M. tuberculosis*.

Kaposi's sarcoma (KS)

The clinical recognition of KS is straightforward when there are typical lesions on the skin and mucous membranes. The diagnosis of pulmonary or pleural KS is more difficult. The patient usually presents with cough, fever and dyspnoea, and usually has KS elsewhere. Chest X-ray shows a diffuse nodular infiltrate or pleural effusion. The pleural fluid is usually blood-stained. Cytology may provide the diagnosis. It can be difficult to rule out concurrent PTB.

Pneumocystis carinii pneumonia (PCP)

PCP is less common in sub-Saharan Africa than in HIV positive populations elsewhere. The patient usually presents with dry cough and progressive dyspnoea. The table below shows the clinical and chest X-ray features which help to distinguish PCP from PTB.



Clinical and chest X-ray features of PCP in contrast with TB

	Typical of PCP	Typical of TB
SYMPTOMS	dry cough sputum mucoid if any dyspnoea	productive cough purulent sputum pleuritic chest pain, haemoptysis
SIGNS	normal fine inspiratory crackles	signs of consolidation signs of pleural effusion
CHEST X-RAY	bilateral diffuse interstitial shadowing normal	lobar consolidation cavitation pleural effusion intrathoracic lymphadenopathy

The definitive diagnosis of PCP rests on finding the cysts in induced sputum, broncho-alveolar lavage or biopsy specimens. These investigations are often unavailable in district hospitals. The diagnosis therefore depends on the clinical and chest X-ray features, exclusion of TB and response to a trial of high-dose cotrimoxazole.

Other conditions

Two other rare conditions are cryptococcosis and nocardiosis. They may present in a similar way to TB. The diagnosis of pulmonary cryptococcosis rests on finding the fungal spores in sputum smears. Nocardiosis may be particularly difficult to differentiate from TB. The chest X-ray often shows upper lobe, cavity infiltrates. The organism may also stain weakly acid-fast. Associated soft-tissue and brain abscesses raise clinical suspicion. The diagnosis rests on finding beaded and branching Gram positive rods on sputum smear.

3 2 EXTRAPULMONARY TB

The common forms of extrapulmonary TB associated with HIV are the following: lymphadenopathy, pleural effusion, pericardial disease, miliary, meningitis. Patients usually present with constitutional features (fever, night sweats, weight loss) and local features related to the site of disease. The local features related to the site of disease are similar in adults and children.

3 2 1 Diagnostic approach

Extrapulmonary TB is common in HIV-positive patients. Many patients with extrapulmonary TB also have co-existent pulmonary TB.

PRACTICAL POINT

If a patient has extrapulmonary TB, look for pulmonary TB. Send sputum samples for AFBs and, if sputum AFBs are negative, do a chest X-ray.

Definitive diagnosis of extrapulmonary TB is often difficult. Diagnosis may be presumptive, provided you can exclude other conditions. The degree of certainty of diagnosis depends on the availability of diagnostic tools, e.g. specialised X-rays, biopsy procedures.

3 2 2 Tuberculous lymphadenopathy

Regardless of HIV status, the lymph nodes most commonly involved are the cervical nodes. The usual course of lymph node disease is as follows:



PRACTICAL POINT

In severe immunocompromise, tuberculous lymphadenopathy may be acute and resemble acute pyogenic lymphadenitis.

The differential diagnosis of tuberculous lymphadenopathy includes the following: persistent generalised lymphadenopathy (PGL), lymphoma, Kaposi's sarcoma, carcinomatous metastases, sarcoid, drug reactions (e.g. phenytoin).

Persistent generalised lymphadenopathy (PGL)

PGL is a feature of HIV infection which develops in up to 50% of HIV infected individuals. There is no specific treatment. The diagnostic criteria for PGL are as follows:

in 2 or more extra-inguinal sites
for 3 or more months duration

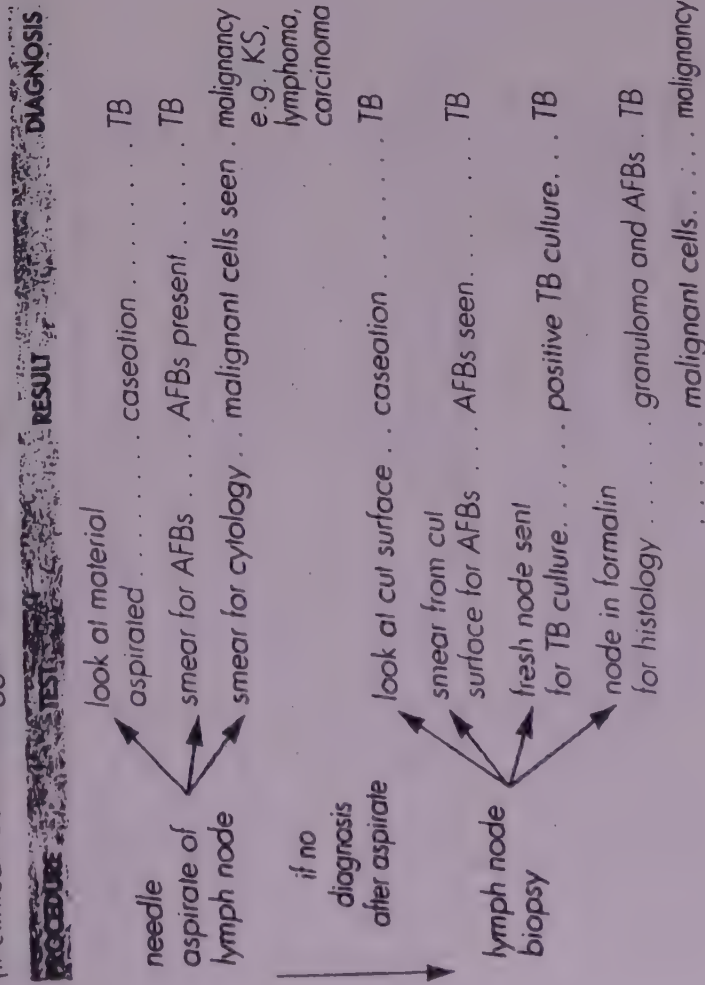
The nodes are non-tender, symmetrical, and often involve the posterior cervical and epitrochlear nodes. PGL may slowly regress during the course of HIV infection and may disappear before the onset of AIDS. In populations with a high HIV prevalence, PGL is the commonest cause of lymphadenopathy. In HIV-positive individuals PGL is a clinical diagnosis. Only investigate further if there are features of another disease. The table below shows the features of lymph nodes which indicate further investigation, including biopsy.

Features of lymph nodes which indicate further investigation

- large (> 4 cm diameter) or rapidly growing lymph nodes,
- asymmetrical lymphadenopathy,
- tender/painful lymph nodes not associated with local infection,
- matted/fluctuant lymph nodes,
- obvious constitutional features (e.g. fever, night sweats, weight loss),
- hilar or mediastinal lymphadenopathy on chest X-ray.

Practical approach to investigation of lymphadenopathy

(if clinical features suggest a cause of lymphadenopathy other than PGL).



laboratory facilities for histology or TB culture. Diagnostic sensitivity of tuberculous lymphadenopathy by aspirate and smear for AFBs is 70%. Diagnostic sensitivity increases to 80% if you excise a lymph node, look at the cut surface, and do a smear for AFBs.

The histological appearance of tuberculous lymph nodes from HIV positive patients depends on the degree of immunocompromise, as shown below.

DEGREE OF IMMUNOCOMPROMISE	HISTOLOGICAL APPEARANCE OF LYMPH NODES
mild	caseating lesions with few or no AFBs
severe	little cellular reaction with many AFBs

3 2 3 Miliary TB

Miliary TB results from widespread blood-borne dissemination of TB bacilli. This is either the consequence of a recent primary infection or the erosion of a tuberculous lesion into a blood vessel.

Clinical features

The patient presents with constitutional features. He may have hepatosplenomegaly and choroidal tubercles (funduscopy). Miliary TB is an under-diagnosed cause of end-stage wasting in HIV-positive individuals

Diagnosis

Chest X-ray shows diffuse, uniformly distributed, small miliary shadows "Miliary" means "like small millet seeds". Full blood count may show pancytopenia. Liver function tests may be abnormal. Bacteriological confirmation is sometimes possible from sputum, C.S.F., or bone marrow.

Differential diagnosis

The differential diagnosis includes the following: slim disease; bacteraemia (including typhoid fever), disseminated carcinoma, disseminated infection with "atypical" mycobacteria, trypanosomiasis (in endemic regions)

3 2 4 Tuberculous serous effusions

Inflammatory tuberculous effusions may occur in any of the serous cavities of the body, i.e. pleural, pericardial or peritoneal cavities. They are a more common form of TB in HIV-positive than in HIV-negative individuals



Approach to diagnosis

The presentation is usually with constitutional and local features. Microscopy of the aspirate from tuberculous serous effusions rarely shows AFBs because the fluid forms as an inflammatory reaction to TB lesions in the serous membrane. TB culture, even if available, is of no immediate help. A culture result usually takes 4-6 weeks. The white cell content is variable, usually with predominant lymphocytes and monocytes. The aspirate is an exudate (i.e. protein content is more than 30 g/l).

PRACTICAL POINT

A biochemistry laboratory is not essential to diagnose an exudate. Simply leave the aspirate standing: if it clots, it is an exudate.

In high HIV prevalence populations in sub-Saharan Africa, TB is the commonest cause of an exudative serous effusion. The diagnosis is usually presumptive (i.e. without microbiological or histological confirmation). It is important to exclude other causes of an exudate.

PRACTICAL POINT

Interpret with caution the laboratory result of protein concentration in any aspirated fluid. If there has been a delay in laboratory analysis, a protein clot may have formed in the sample. The laboratory result may be falsely low.

TUBERCULOUS PLEURAL EFFUSION

The clinical and chest X-ray diagnosis of a pleural effusion is straightforward. The typical clinical features are constitutional and local (chest pain, breathlessness, tracheal and mediastinal shift away from the side of the effusion; decreased chest movement, percussion note and breath sounds on the side of the effusion). Chest X-ray shows unilateral, uniform white opacity, often with a concave upper border. If available, ultrasound confirms the presence of fluid in the pleural space in case of doubt.

Always perform diagnostic pleural aspiration if a patient has a pleural effusion. The fluid is usually straw-coloured. The white cell count is usually

high (about 1,000 - 2,500 per mm³) with predominant lymphocytes. Occasionally the fluid is blood-stained. The presence of pus on aspiration indicates an empyema (purulent effusion).

PRACTICAL POINT

In a hospital with limited facilities serving a high TB prevalence population you should treat a patient with a unilateral exudative pleural effusion with anti-TB drugs.

If facilities are available, closed pleural biopsy using an Abrams needle is useful for histological diagnosis. Since the distribution of TB lesions in the pleura is patchy, the diagnostic yield of closed pleural biopsy is about 75%. Multiple biopsies increase the diagnostic yield. A small open pleural biopsy increases the yield even further but is not usually necessary.

Differential diagnosis

The differential diagnosis of an exudative pleural effusion includes malignancy, post-pneumonic effusion, pulmonary embolism and amoebic liver abscess (extending on the right).

TUBERCULOUS EMPYEMA

This usually arises when a tuberculous cavity in the lung ruptures into the pleural space. The physical signs are those of a pleural effusion, but aspiration reveals thick white/yellow pus. If the pus is too thick to remove using a needle and syringe, use an intercostal drain. Send the pus to the laboratory for examination for TB and also for Gram stain and bacterial culture. If facilities are available, closed pleural biopsy is useful for histological diagnosis.

The main differential diagnosis is bacterial empyema, when the patient is usually more acutely ill and toxic. It may be possible to confirm bacterial empyema by Gram stain and/or culture of the aspirated pus.

A succussion splash is a splashing sound heard with the stethoscope while shaking the patient's chest. A succussion splash indicates a pyopneumothorax (pus and air in the pleural space). After chest X-ray confirmation, insert a chest drain with underwater seal.

Always test a patient with signs of a pleural effusion for a succussion splash.

TUBERCULOUS PERICARDIAL EFFUSION

Diagnosis

The diagnosis usually rests on suggestive constitutional and cardiovascular features and investigation findings (ECG, chest X-ray and echocardiography). It is important to exclude uraemia and Kaposi's sarcoma.

Cardiovascular symptoms

- chest pain
- shortness of breath
- cough
- dizziness and weakness (low cardiac output)
- leg swelling
- right hypochondrial pain (liver congestion)
- abdominal swelling (ascites)

Cardiovascular signs

- tachycardia
- low blood pressure
- pulsus paradoxus
- raised jugular venous pressure (JVP) with small amplitude "a" and "v" waves
- impalpable apex beat
- quiet heart sounds
- pericardial friction rub
- signs of right-sided heart failure (e.g. hepatomegaly, ascites, oedema)

PRACTICAL POINT

The signs may be subtle. Assess carefully any patient with oedema and/or ascites with the possibility of pericardial effusion in mind.



- large globular heart
- clear lung fields
- pleural fluid

ECG

- tachycardia
- ST and T wave changes
- low voltage QRS complexes

Echocardiography

- pericardial fluid
- strands crossing between visceral and parietal pericardium

Pitfalls in diagnosis of pericardial effusion

Clinicians have mis-diagnosed pericardial effusion as the following:

- congestive cardiac failure;
- hepatoma or amoebic liver abscess (enlarged liver);
- bilateral pleural effusions.

Pericardiocentesis

This is only safe under the following conditions:

- a) echocardiography has confirmed a moderate to large pericardial effusion;
- b) the operator is experienced.

Therapeutic pericardiocentesis is necessary if there is cardiac tamponade (acute life-threatening cardiac impairment).

PRACTICAL POINT

In high TB/HIV prevalence populations, TB is the most likely treatable cause of pericardial effusion. It may be safer for the patient to start presumptive anti-TB treatment rather than undergo diagnostic pericardiocentesis.

Treatment with steroids and anti-TB drugs, without pericardiocentesis, usually results in satisfactory resolution of tuberculous pericardial effusion.



Outcome

A possible complication despite TB cure is the development of pericardial constriction. Medical management of heart failure due to pericardial constriction helps in some cases. A surgeon may weigh up the possible benefit to the patient of pericardiectomy, set against the operative risks.

Differential diagnosis

Apart from TB, the differential diagnosis of pericardial effusion includes the following:

TRANSUDATES uraemia, heart failure, liver failure

EXUDATES malignancy, bacterial pericardial empyema, inflammatory diseases, hypothyroidism

TUBERCULOUS ASCITES

Ascites results from peritoneal TB. Routes of spread of TB to the peritoneum include the following:

- a) from tuberculous mesenteric lymph nodes;
- b) from intestinal TB (pulmonary TB patients may develop intestinal ulcers and fistulae as a result of swallowing infected sputum);
- c) blood-borne.

Clinical features

Patients present with constitutional features and ascites. There may be palpable abdominal masses (mesenteric lymph nodes). Adhesion of nodes to bowel may cause bowel obstruction. Fistulae may develop between bowel, bladder and abdominal wall.

Investigations

Do a chest X-ray to look for associated PTB. Always do a diagnostic ascitic tap. The aspirated fluid is usually straw-coloured, but occasionally turbid or blood-stained. The fluid is an exudate, usually with more than 300 white cells per mm³ and predominantly lymphocytes. Ultrasound, if available, may show features consistent with TB, including enlarged mesenteric or retroperitoneal lymph nodes.

PRACTICAL POINT

An ill, wasted patient with TB ascites may have a low serum albumin concentration. In this case, the usual threshold of 30 g/l albumin concentration for diagnosing an exudate is too high. Instead, calculate the difference between the albumin concentrations in serum and ascites. A serum - ascites albumin difference of less than 11 g/l means that the ascites is an exudate.

Diagnosis

The diagnosis is usually presumptive. Definitive diagnosis rests on a peritoneal biopsy, available in some hospitals. Blind percutaneous needle biopsy of the peritoneum has a low pick-up rate and a high complication rate. In experienced hands, laparoscopy under local anaesthetic has a high pick-up rate. Laparoscopy enables direct visualisation and biopsy of peritoneal TB lesions. Laparotomy will confirm the diagnosis in nearly every case but is too invasive for routine use.

Differential diagnosis

Apart from tuberculosis, the differential diagnosis of ascites includes the following:

TRANSUDATES heart failure, renal failure, nephrotic syndrome, liver failure, hypoproteinaemia;

EXUDATES malignancy, other infections causing peritonitis.

3 2 5 Tuberculous meningitis

Routes of spread of TB to the meninges include the following:

- a) from rupture of a cerebral tuberculoma into the subarachnoid space;
- b) blood-borne.

Clinical features

The patient may present with constitutional features and a chronic meningitis. There is gradual onset and progression of headache and decreased consciousness. Examination often reveals neck stiffness and a

positive Kernig's sign. Cranial nerve palsies occur from increased pressure at the base of the brain. Tuberculomas and vascular occlusion may cause focal neurological deficits and seizures. Obstructive hydrocephalus may develop. Spinal meningeal involvement causes paraplegia (spastic or flaccid).

Diagnosis

The diagnosis usually rests on clinical grounds and cerebrospinal fluid (C.S.F.) examination. In most cases of clinically suspected TB meningitis, lumbar puncture is safe.

PRACTICAL POINT

Lumbar puncture is hazardous if the patient has a focal neurological deficit (cerebral space-occupying lesion) or if fundoscopy shows papilloedema (raised intra-cranial pressure). In these circumstances, a C.A.T. brain scan is helpful, if available. Otherwise, it may be safer to start presumptive treatment with anti-TB drugs rather than risk lumbar puncture.

The C.S.F. opening pressure is high. The C.S.F. may look clear or cloudy. The white cell count is usually about 500 per mm³ with predominantly lymphocytes (or early in the course of infection, predominantly polymorphs). Usually the protein level is high and the glucose low. C.S.F. microscopy shows AFBs in a minority of cases. It is possible to increase the diagnostic pick-up rate by the following:

- examine the deposit on centrifugation of a 10 ml C.S.F. sample;
- examine the deposit for at least half an hour before reporting it as negative;
- examine several C.S.F. samples obtained over a few days.

PRACTICAL POINT

Always exclude cryptococcal meningitis by C.S.F. microscopy (India ink stain) and, if available, fungal culture.



Some of the C.S.F. findings may be normal, especially in early patients. The percentages of HIV-positive TB meningitis patients with normal C.S.F. findings are as follows: glucose 15%, protein 40%, white cell count 10%.

Differential diagnosis

The table below shows the differential diagnosis of TB meningitis, with typical C.S.F. abnormal findings.

Differential diagnosis of tuberculous meningitis

CSF ABNORMALITIES

DISEASE	CSF WHITE CELLS	PROTEIN	GLUCOSE	MICROSCOPY
tuberculous... meningitis	Elevated L > PMN	Increased	Decreased	AFB (in some cases)
cryptococcal*... meningitis	Elevated L > PM	Increased	Decreased	Positive India ink staining
partially*... treated bacterial meningitis	Elevated	Increased	Decreased	Bacteria on Gram stain (rarely)
viral... meningitis	Elevated L > PMN	Increased	Normal (low in mumps or H.simplex)	
acute... syphilis	Elevated L > PMN	Increased	Normal	
late stage... trypanosomiasis	Elevated L > PMN	Increased	Decreased	Motile trypanosomes
tumour... (carcinoma/ lymphoma)	Elevated L > PMN	Increased	Decreased	Cytology shows malignant cells
leptospirosis	Elevated L > PMN	Increased	Decreased	Leptospire
amoebic... meningitis	Elevated L > PMN	Increased	Decreased	Amoebae

PMN = polymorphonuclear leucocytes; L = lymphocytes
* common differential diagnoses



3 2 6 Other forms of extrapulmonary TB

Other forms of extrapulmonary tuberculosis are less common. There is no information as to whether they occur any more frequently in HIV-positive than in HIV-negative individuals. The table below shows the usual clinical features and diagnostic tests.

Other forms of extrapulmonary TB

SITE OF DISEASE	CLINICAL FEATURES	DIAGNOSIS
Spine	Back pain Gibbus Psoas abscess Radicular pain Spinal cord compression ✓	Plain X-ray Tissue biopsy
Bone	Chronic osteomyelitis	Tissue biopsy
Peripheral joints	Usually monoarthritis	Plain X-ray Synovial biopsy
Gastrointestinal	Abdominal mass Diarrhoea	Barium X-rays
Liver	Right upper quadrant pain and mass	Ultrasound and biopsy
Renal and urinary tract	Urinary frequency Dysuria Haematuria Loin pain / swelling	Sterile pyuria Urine culture Intravenous pyelogram
Adrenal gland	Features of hypoadrenalism (hypotension, low serum sodium, normal/high potassium, raised urea, low glucose)	Plain X-ray (calcification) Ultrasound
Upper respiratory tract	Hoarseness Pain in ear Pain on swallowing	Usually complication of pulmonary disease
Female genital tract	Infertility Pelvic inflammatory disease Ectopic pregnancy	Pelvic examination X-ray genital tract Tissue biopsy
Male genital tract	Epididymitis	Often evidence of renal/urinary tract TB

3 2 7 Further information on spinal, gastrointestinal and hepatic TB

Spinal TB.

Tuberculosis of the spine is important. The disastrous consequence for the patient of a missed diagnosis of thoracic or cervical spinal TB is paralysis. TB starts in an intervertebral disc, spreads along the anterior and longitudinal ligaments, then involves the adjacent vertebral bodies. In areas of high TB prevalence, plain X-ray of the spine is usually diagnostic. The typical appearance is erosion of the anterior edges of the superior and inferior borders of adjacent vertebral bodies. The disc space is narrowed. The sites most commonly involved are the lower thoracic, lumbar and lumbosacral.

The main differential diagnoses are malignancy and pyogenic spinal infections. Malignant deposits in the spine tend to erode the pedicles and spinal bodies, leaving the disc intact. Pyogenic infection tends to be more acute than TB with more severe pain.

Gastrointestinal TB.

Ileo-caecal TB may present with constitutional features, chronic diarrhoea, subacute obstruction, or a right iliac fossa mass. Diagnosis rests on barium examination of the small and large bowel, or on colonoscopy, if available. The differential diagnosis includes ileo-caecal Crohn's disease, carcinoma of the caecum, appendix abscess, lymphoma, amoeboma and tubo-ovarian abscess.

Hepatic TB

Miliary TB may involve the liver. Hepatic TB can cause diagnostic confusion. Solitary or multiple TB abscess formation can mimic amoebic liver abscess. Nodular hepatic TB can mimic hepatoma. In these situations, ultrasound examination is useful. Liver biopsy, available in some hospitals, is diagnostic.

SUGGESTIONS FOR FURTHER READING

Toman K. *Tuberculosis. Case finding and chemotherapy.* Geneva: WHO, 1979.

Crofton J, Horne N and Miller F. *Clinical Tuberculosis. The MacMillan Press Limited.* 1992.

Davies PDO. *Clinical Tuberculosis. Chapman and Hall Medical.* 1994

Transmission of TB to children

The source of transmission of TB to a child is usually an adult (usually a family member) with sputum smear-positive PTB.

Public health importance

Cases of TB in children usually represent between 5-15% of all TB cases. The frequency of childhood TB in a given population depends on the following: the number of infectious cases, the intensity of transmission, and the age structure of the population. Children rarely have sputum smear-positive TB. So they are rarely infectious. TB in children is therefore due to failure of TB control in adults. Failure of TB control in adults means failure to cure the infectious cases (patients with sputum smear-positive PTB).



PRACTICAL POINT

A good TB control programme is the best way to prevent TB in children.

The highest priority in TB control is to cure the infectious cases. Children are rarely infectious. However, it is still important to cure them! Good treatment of TB in childhood will result in the following: a) decreased morbidity and mortality; b) improved NTP credibility and reputation.

Risk of infection

Risk of infection depends on 2 factors: a) extent of exposure to infectious droplet nuclei, and b) susceptibility to infection. Consider an infant whose mother has sputum smear-positive PTB. The infant has a high risk of acquiring infection: he is in very close contact with his mother; his immune defences are poor. An infant with HIV infection has an even greater susceptibility to infection with tubercle bacilli.

Risk of progression of infection to disease.

The vast majority of HIV-negative children infected with *M. tuberculosis* do not develop TB disease. In these healthy, asymptomatic, but TB-infected children, the only evidence of infection may be a positive tuberculin skin



test. However, an infected child can develop TB disease at any time. The chance of developing disease is greatest shortly after infection and then steadily decreases as time goes by. Various physical or emotional stresses may trigger progression of infection to disease. The most important trigger is weakening of immune resistance, especially by HIV infection. Other important triggers include the following: other infections (especially measles and whooping cough) and malnutrition.

Pathogenesis

The usual route of infection and early sequence of events in primary pulmonary infection are similar in adults and children. TB disease in children is usually primary TB. A child may have asymptomatic *M. tuberculosis* infection: the tubercle bacilli can lie dormant for many years. If the tubercle bacilli reactivate some years later, causing post-primary TB, the child has usually grown into an adult by then. The age when a child is infected determines the pattern of primary disease. Up to puberty, blood-borne spread is common. This results in disseminated (miliary and extrapulmonary) disease. After puberty, pulmonary spread is more common.

PRACTICAL POINT

Malnourished children may develop severe PTB at any age.

2 APPROACH TO DIAGNOSIS

If you find the diagnosis of TB in children easy, you are probably over-diagnosing TB. If you find the diagnosis of TB in children difficult, you are not alone. It is easy to over-diagnose TB in children. It is also easy to miss TB in children. Carefully assess all the evidence before making the diagnosis.

Adults with PTB usually present with cough and sputum. Although sputum culture is the definitive test, in practice the readily available usual "gold standard" test for adults with PTB is sputum smear microscopy. However, there is no such "gold standard" test in children. TB in children is a general disease which may appear in any part of the body. Also, under the age of 10 years, children with PTB rarely cough up sputum. They usually swallow their sputum. Gastric suction and laryngeal swabs are generally not useful unless facilities are available for *M. tuberculosis*

culture. The diagnosis of TB in children is therefore nearly always presumptive. This means that bacteriological confirmation is usually not possible. This situation in children is similar to that in adults with sputum smear-negative PTB or extrapulmonary TB.

The clinical features are constitutional and local (depending on the part of the body affected). The local clinical features related to the site of disease are similar in children and adults (see Chapter 3 for details). The diagnosis rests on consistent clinical features and investigation findings. If available, a tuberculin skin test may be helpful. In most cases of suspected PTB, the child has usually received treatment with a broad-spectrum antibiotic, with no clinical response. In some hospitals, helpful special diagnostic investigations may be available. These may include specialised X-rays, biopsy and histology, and TB culture.

Always look for the following 2 important clues to TB in children:
1) it is usually possible to identify the adult source of infection;
2) failure to thrive or weight loss (growth faltering).
In the absence of these 2 clues, TB is less likely.

PRACTICAL POINT

Ask the mother of a child with suspected TB for the child's "road to health" card (growth card). Look at the card for growth faltering or weight loss.

3 SCORE SYSTEM FOR THE DIAGNOSIS OF TB IN CHILDREN

A score system is one way of trying to improve the diagnosis of childhood TB. The basis of a score system is the careful and systematic collection of diagnostic information. A score system helps guide your clinical judgment. A score above a certain threshold indicates a high likelihood of TB. The table shows a score chart (adapted from Crofton, Horne and Miller) for helping to diagnose childhood TB. A score of 7 or more indicates a high likelihood of TB.

SCORE IF FEATURE PRESENT					
Feature	0	1	2	3	4
General					
duration of illness (weeks)	<2	2-4		>4	
nutrition (%weight for age)	>80	60-80		<60	
family history of TB	none	reported by family		proved sputum positive	
tuberculin test				positive	
malnutrition				not improving after 4 weeks	
unexplained fever and night sweats			no response to malaria treatment		
local					
				lymph nodes	
				joint or bone swelling	
				abdominal mass or ascites	
				C.N.S. signs, and usually abnormal C.S.F. findings	
				angle deformity of spine	
TOTAL SCORE					



This is a controversial topic. In the past, some doctors have advocated a treatment trial with anti-TB drugs as a diagnostic manoeuvre. The idea is that if the child responds to treatment with anti-TB drugs, then the diagnosis is TB. There are some problems with this approach:

- a) some anti-TB drugs also kill other bacteria, so response to anti-TB drugs may be because the child has another (bacterial) infection;
- b) compliance with a "treatment trial" is often poor, because of the lack of certainty surrounding the decision to treat;
- c) there may be a tendency to jump too quickly to a "treatment trial" without the necessary careful and thoughtful approach to diagnosis.

On account of these problems, it is better to try to come to a decision: yes, the child has TB; or, no, the child does not have TB. The process of coming to a decision is an active process. The process involves weighing up the clinical evidence and investigation findings, careful thought, and often a period of observation.

4 5 TUBERCULIN SKIN TEST

Tuberculin is a purified protein derived from tubercle bacilli. Thus, another name for tuberculin is PPD (Purified Protein Derivative). Following infection with *M. tuberculosis*, a person develops hypersensitivity to tuberculin. Tuberculin injected into the skin of an infected person produces a delayed local reaction after 24-48 hours. We quantify this reaction by measuring the diameter of skin induration (thickening) at the site of the reaction. Various conditions may suppress this reaction. The reaction indicates **hypersensitivity**. In other words, the reaction only shows that the person has at some time had infection with *M. tuberculosis*.

PRACTICAL POINT

A tuberculin test does not measure immunity. By itself, it does not indicate the presence or extent of tuberculosis disease; it only indicates infection.

The technical details about tuberculin and how to administer and read a tuberculin test are beyond the scope of this book. "Clinical Tuberculosis" (Crofton, Horne and Miller) gives a good account.



Value of a negative tuberculin test

A tuberculin test is negative when the diameter of skin induration is less than 10 mm. This is regardless of whether or not the person has had BCG. A negative tuberculin skin test does not exclude TB. In other words, a negative test is of no help in deciding that someone does not have TB. The table shows the conditions which may suppress a tuberculin skin test in a person with active TB.

CONDITIONS WHICH MAY SUPPRESS THE TUBERCULIN SKIN TEST

- HIV infection
- Malnutrition
- Severe bacterial infections, including TB itself
- Viral infections, e.g. measles, chickenpox, glandular fever
- Cancer
- Immunosuppressive drugs, e.g. steroids

Value of a positive tuberculin skin test

The criterion for a positive tuberculin test depends on whether a child has previously had BCG vaccination or not. This is because a reaction to tuberculin is usual after a previous BCG, at least for several years. This reaction is usually a weaker reaction (diameter often less than 10 mm) than the reaction to natural infection with *M. tuberculosis*. Therefore, in a child who has not had BCG, a tuberculin test is positive when the diameter of skin induration is 10 mm or more. In a child who has had BCG, a test is positive when the diameter of induration is 15 mm or more. A positive tuberculin test is only one piece of evidence in favour of the diagnosis of TB. The younger the child and the greater the diameter of induration (above 10-15 mm), the stronger is that one piece of evidence.

6 THE IMPACT OF HIV ON THE DIAGNOSIS OF TB IN CHILDREN

HIV makes the diagnosis of TB in children even more difficult than usual, for the following reasons:

- Several HIV-related diseases, including TB, may present in a similar way (see section 4.7 for differential diagnosis).
- The interpretation of tuberculin skin testing is even more unreliable than usual. An immunocompromised child may have a negative tuberculin skin test despite having TB.
- A child with HIV infection usually comes from a household where the

parents have HIV infection. One or both parents may have died from AIDS. It may be difficult for the child to attend a health facility.

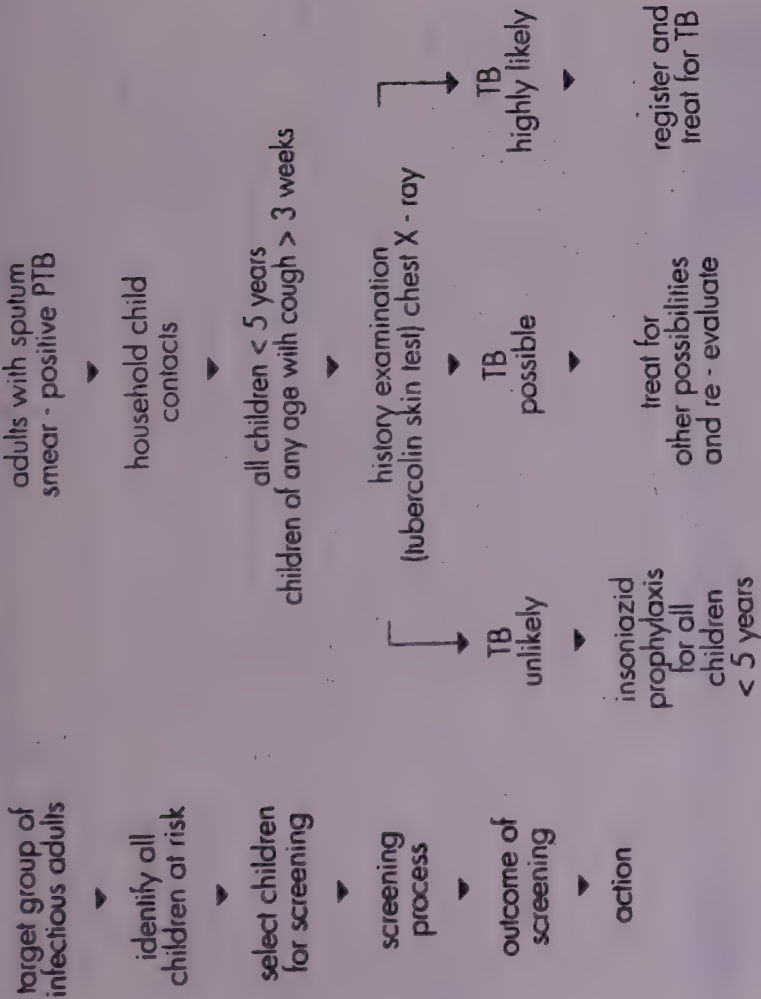
7 DIFFERENTIAL DIAGNOSIS OF PTB IN HIV-INFECTED CHILDREN

- bacterial pneumonia
- viral pneumonia, e.g. cytomegalovirus
- fungal pneumonia, e.g. candida, cryptococcus
- Pneumocystis carinii* pneumonia
- lymphocytic interstitial pneumonitis
- pulmonary lymphoma

8 MANAGEMENT OF CHILD CONTACTS OF INFECTIOUS ADULTS

Children with TB may present to health units when they are ill. However, most National TB Control Programmes also recommend active contact tracing of children who are household contacts of infectious adults. In order to be effective, this screening must be systematic. If you don't have a systematic, organised process for child contact screening where you work, could you start one?

The scheme below shows how to manage child contacts of infectious adults (with sputum smear-positive PTB). Suspicion that a child contact is HIV-infected may arise because of the following: the child has clinical evidence of HIV infection; the parent (the infectious TB patient) is known, or suspected to be, HIV-positive. If you suspect a child contact is HIV-infected, it is important to counsel the parents before HIV-testing the child.



Consider a child under 5 years of age living with a sputum smear-positive PTB patient. This child household contact is at high risk of TB infection and developing TB disease, especially if HIV-positive. Tuberculin skin testing is often not available. Also, tuberculin skin testing is not a reliable way of distinguishing TB-infected from non-TB-infected children. The IUATLD therefore recommends isoniazid preventive treatment for all child household contacts (under 5 years of age) of sputum smear-positive PTB patients.

SUGGESTIONS FOR FURTHER READING

- Miller FJW. *Tuberculosis in children*. New Delhi: Churchill-Livingstone, 1986.
- Chaulet P and collaborators. *Children in the Tropics*. Childhood tuberculosis, still with us. International Children's Centre, Paris, 1992.
- Crofton J, Horne N and Miller F. *Clinical Tuberculosis*. The MacMillan Press Limited, 1992.
- International Union Against Tuberculosis and Lung Disease. *Tuberculosis guide for low-income countries*. pmi Verlagsgruppe. 3rd edition. Frankfurt, 1994.
- Topley JM, Maher D, Mbewe LN. *Transmission of tuberculosis to contacts of sputum positive adults in Malawi*. Arch Dis Child 1996; 74: 140-143.



5.1 CLINICAL RECOGNITION OF HIV INFECTION IN TB PATIENTS

In many TB/HIV patients in sub-Saharan Africa, the only HIV-related illness present is TB. However, certain clinical features are more common in HIV-positive TB patients than in HIV-negative TB patients. The table below shows these clinical features suspicious of HIV infection.

CLINICAL FEATURES SUSPICIOUS OF HIV CO-INFECTION IN TB PATIENTS

Past history	sexually transmitted disease (STD) herpes zoster (shingles) recurrent pneumonia bacteraemia (especially <i>Salmonella typhimurium</i>)
Symptoms	weight loss (> 10 kg or > 20% of original weight) diarrhoea (> 1 month) pain on swallowing (suggests oesophageal candida) burning sensation of feet (peripheral sensory neuropathy)
Signs	scar of herpes zoster pruritic papular rash Kaposi's sarcoma symmetrical generalised lymphadenopathy oral candidiasis oral hairy leukoplakia persistent painful genital ulceration

PRACTICAL POINT

Full blood count (FBC) findings suspicious of HIV infection are unexplained anaemia, leucopenia or thrombocytopenia.

The definitive diagnosis of HIV infection rests on a positive HIV test.



5.2 HIV TESTING

5.2.1 HIV tests

There are different ways of testing for HIV. The most widely available way of identifying HIV-infected individuals is the detection of HIV antibodies in serum or plasma samples. The table below shows the 3 main methods of HIV-testing. The technical details of these tests are beyond the scope of this manual, but there is a good account in "AIDS in Africa: a manual for physicians".

HIV TESTING METHODS WITH ADVANTAGES AND DISADVANTAGES

HIV TESTING METHOD	ADVANTAGES	DISADVANTAGES
ELISA	less expensive than immunoblot	some specialised laboratory equipment necessary
immunoblot	large numbers of sera can be tested daily	sensitive and specific
simple/rapid (e.g. rapid immuno-binding assay)	simple, rapid	older tests less sensitive and less specific but newer tests improved
immunoblot	most sensitive and specific	expensive specialised laboratory equipment necessary

The usual type of test for HIV antibodies is the ELISA (Enzyme-linked ImmunoSorbent Assay). The cost per individual ELISA test is about US \$0.75-1.75. There are ELISA tests available which test for both HIV-1 and HIV-2.

5.2.2 Objectives of HIV antibody testing in TB patients

There are 3 main possible objectives in performing HIV antibody tests in TB patients:

- a) diagnosis of HIV infection in individual TB patients;
- b) surveillance (anonymous testing to monitor epidemiological trends);
- c) research (voluntary testing for epidemiological, clinical, or virological studies)

5.2.3 Strategy for HIV antibody testing in TB patients (Which tests to use and when to use them)

HIV testing methods vary in accuracy and cost. In general, WHO recommends different HIV-testing strategies, depending on the objective of testing. The aim is to maximise accuracy and minimise cost. The table below shows the strategy appropriate for the objective of testing

OBJECTIVES, STRATEGIES AND INTERPRETATION OF HIV TESTS

OBJECTIVE	TESTING STRATEGY	INTERPRETATION OF RESULTS
Diagnosis of HIV infection in individual TB patients (a group with a high HIV sero-prevalence)	Test sample with ELISA or simple/rapid assay	1 st assay negative = patient HIV negative
	If 1 st assay positive, re-test using ELISA or simple/rapid assay based on a different antigen preparation or test	1 st assay positive + 2 nd assay positive = patient HIV positive
Surveillance (in population with HIV prevalence > 10%)	Test sample with ELISA or simple/rapid assay	1 st assay positive + 2 nd assay negative -> repeat both assays
		Results remain discordant -> repeat sample and testing
		Assay negative = patient HIV negative
		Assay positive = patient HIV positive

Many low-income countries cannot afford the cost of the strategy of 2 positive tests in order to diagnose HIV infection in an individual patient. In practice, a patient has 1 test only: test negative = patient HIV negative; test positive = patient HIV positive.

5.2.4 Diagnosis of HIV infection in individual TB patients

The link between HIV and TB is well known to many members of the public. A patient with TB may therefore be well aware of the possibility he also has HIV infection. It is important to offer counselling and voluntary HIV testing, if available, to TB patients on account of the following possible benefits:

- the patient may want the chance to know his HIV status;
- better diagnosis and management of other HIV-related illnesses;
- avoidance of drugs associated with a high risk of side-effects;
- increased condom use and decreased HIV transmission.

PRACTICAL POINT

Anti-TB drug treatment is the same for HIV-positive and HIV-negative TB patients, with one exception: do not give thiacetazone to HIV-positive TB patients (increased risk of severe and sometimes fatal skin reactions).

A policy of compulsory HIV testing (even if this were legal) of TB patients would be counter-productive. This type of policy would have the following results:

- patients deterred from seeking care;
- decreased case-finding in at-risk groups;
- reduced credibility of health services.

5.3 HIV COUNSELLING

Confidential counselling is essential before and after HIV antibody testing. The patient gives explicit informed consent to have the test, i.e. he understands what the test involves and the implications of testing. The counsellor provides support. Counselling is a dialogue between patient and counsellor.



Counsellors

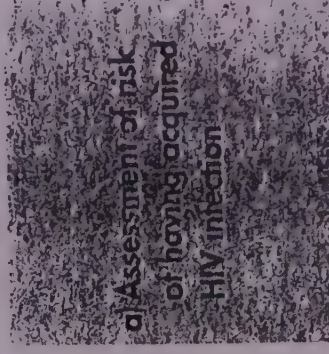
With suitable training, anyone who works with patients and families can be a counsellor. Counsellors may be members of the community or health workers. Many health workers have had counselling training. In the course of their duties they have the opportunity to counsel patients for HIV testing. Doctors and other clinicians are often in a good position to counsel patients for HIV testing. This is because clinicians have already established a relationship with the patient, who usually trusts the clinician.

Pre-test counselling

The aim is to enable the patient to make an informed decision to have the test or not. The patient needs to know what the test involves and what are the implications of the result. The main issues for discussion are assessments of the following: a) the patient's likelihood of having acquired HIV infection, b) his knowledge about HIV, and c) his ability to cope with a positive result

PRACTICAL POINT

In sub-Saharan Africa, anyone with TB is in a high risk group for HIV.

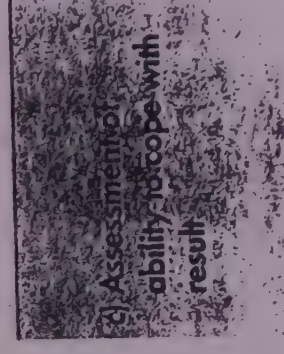


a) Assessment of risk of having acquired HIV infection

- multiple sex partners
- sex with commercial sex workers
- for men, sex with other men
- non-sterile skin piercing, e.g. scarification, tattooing
- previous blood transfusion
- intravenous drug use
- sexual partner/spouse of person at risk

b) Assessment of knowledge about HIV

- what does the test involve and mean?
- how does HIV transmission occur?
- what is high risk behaviour?



c) Assessment of ability to cope with result

- patient's expected reaction to result
- who will provide emotional support?
- impact of a positive result on
 - relationships
 - social issues, e.g. employment
 - future health



PRACTICAL POINT

The HIV test does not become positive until usually 6 weeks, and up to about 3 months, after infection (the "window period").

Post-test counselling

The content of post-test counselling depends on the HIV test result. The aims are to discuss the result, share information, provide support, and encourage future safe sexual behaviour. Always ensure confidentiality. Break the news openly and sympathetically. When someone has a positive HIV test result, common reactions at different times may include shock, anger, guilt, grief and depression. Patients will need continuing support.

Issues for discussion when the HIV test result is negative.

- A negative result does not mean that the patient definitely does not have HIV infection (the test could be in the seroconversion "window period").
- Avoidance of unsafe sexual behaviour.
- Promotion of healthy behaviour.

Issues for discussion when the HIV test result is positive.

- General health (good diet, balance of rest and exercise, avoiding infections, when to seek advice about symptoms of other HIV-related illnesses).
- Awareness of possible anti-TB drug side-effects.
- Safe sexual behaviour.
- Avoidance of blood or organ donation.
- The patient's reaction to the test result.
- Emotional and psychological support for the patient.
- How to tell friends, family and lovers.
- Counselling partner(s) if possible.
- Referral to local community services and support groups, if available.
- Social implications, e.g. employment, life insurance.

SUGGESTIONS FOR FURTHER READING

WHO. AIDS in Africa: a manual for physicians. Geneva, 1992.

WHO. Weekly Epidemiological Record. 1992; 67: 145-149.

WHO. Guidelines for HIV Surveillance Among Tuberculosis Patients. Geneva, 1994.

WHO. Global Programme on AIDS. Source Book for HIV/AIDS Counselling Training. GE, 1994.

WHO. Global Programme on AIDS. Counselling for HIV/AIDS: a key to caring. GE, 1995.

WHO. Global Programme on AIDS. Living with AIDS in the community. GE, 1992.

CHAPTER 6

DIAGNOSIS OF HIV IN CHILDREN WITH TUBERCULOSIS

6

1

CLINICAL RECOGNITION OF HIV INFECTION IN CHILDREN

HIV infection in children may show in many ways. The clinical signs are often not specific for HIV infection. For example, weight loss, fever and cough are common in TB, with or without HIV infection. The clinical definition of HIV infection is therefore difficult.

PRACTICAL POINT

Parents provide important clues to possible HIV infection in their children. Ask the parents about their health. Sometimes parents may reveal their own HIV status.

The table below shows clinical signs suspicious of HIV infection in children.

CLINICAL SIGNS SUSPICIOUS OF HIV INFECTION IN CHILDREN

- weight loss or abnormally slow growth
- chronic diarrhoea (> 1 month)
- prolonged fever (> 1 month)
- generalised lymph node enlargement
- oropharyngeal candidiasis
- recurrent common infections, e.g. ear infections, pharyngitis
- persistent cough
- generalised rash
- neurological problems
- delay in development
- bilateral parotid gland enlargement
- enlarged spleen
- enlarged liver
- recurrent abscesses
- meningitis
- recurrent herpes simplex

Positive and negative HIV tests are not always reliable. Rarely, a baby with HIV infection has a negative HIV antibody test. The reason for this is not known.

The definitive diagnosis of HIV infection rests on a positive HIV test. However, a positive HIV antibody test is not a reliable indicator of HIV infection in early childhood (up to 18 months of age). During the pregnancy of a mother with HIV infection, the mother's antibodies to HIV cross the placenta. Therefore almost all children born to HIV-positive mothers have HIV antibodies in their blood at birth. However, only about one third of children born to HIV-infected mothers are infected. Initially, HIV antibody testing cannot therefore distinguish uninfected from infected children. In **uninfected** children, these maternal antibodies usually become undetectable by 9 months of age. Occasionally maternal antibodies remain detectable until 18 months. Most **infected** children make their own antibodies; so the HIV antibody test will still be positive after 18 months.

PRACTICAL POINT

In children under 18 months, the diagnosis of HIV infection rests on clinical features in the baby and a positive HIV test in the mother.

A child with suspected HIV generally means a family with suspected HIV. Counselling therefore has to take into consideration the mother and, if possible, the father. See Chapter 5 for the issues for discussion with adults with suspected HIV.

Pre-test counselling

It is important to counsel the mother and obtain her consent before testing her blood (if the child is under 18 months) or the child's blood (if the child is over 18 months) for HIV. If her child tests HIV positive, then it is extremely likely that she is the source of infection and is HIV positive.



have HIV infection:

- her child may have an incurable and fatal disease;
- she herself may have HIV;
- her husband may have HIV;
- any future children may have HIV.

Her decision to have a test or not is difficult. She will need time and support while she considers the advantages and disadvantages of a test. If she knows she is HIV-positive, the main advantage is that she can plan for the future. The main disadvantage is the fear that her husband may beat her or leave her if she tells him that she is HIV-positive.

PRACTICAL POINT

The mother may like to bring her husband for joint pre-test counselling. It is usually easier for a woman to tell her husband she may be HIV-positive than to tell him afterwards that she is HIV-positive.

Post-test counselling

Consider a mother whose child has TB and suspected or known HIV infection. See Chapter 5 for the issues for discussion relevant to anyone who tests HIV-positive. There are other issues specific to a mother who tests HIV-positive. These include the poor outlook for the child and the risk for future babies of HIV infection. About one third of children born to HIV-positive women are also HIV-infected.

When counselling women who are breast-feeding or who have delivered recently it is important to discuss breast-feeding. There may be a small risk of HIV transmission by breast-feeding. However, in many low-income countries, breast-feeding is still a safer alternative to bottle-feeding. For example, consider a child whose mother is HIV-positive and who lives in an environment where there is no clean water. The child is probably at higher risk of dying from diarrhoea if bottle-fed than from AIDS if breastfed.



SUGGESTIONS FOR FURTHER READING

Chintu C, Bhat G, Luo C, et al. Seroprevalence of human immunodeficiency virus type 1 in Zambian children with tuberculosis. *Pediatr Infect Dis J* 1993; 12: 499-504.

Sassan-Morokro M, De Cock KM, Ackah A, et al. Tuberculosis and HIV infection in children in Abidjan, Cote d'Ivoire. *Trans Royal Soc Tr Med and Hygiene* 1994; 88: 178-181.

WHO: Global Programme on AIDS. Source Book for HIV/AIDS Counselling Training. Geneva, 1994.

WHO Global Programme on AIDS. Counselling for HIV/AIDS: a key to caring. Geneva, 1995.



CHAPTER 7 STANDARDISED TB CASE DEFINITIONS AND TREATMENT CATEGORIES

7 1 STANDARDISED CASE DEFINITIONS

7 1 1 Introduction

The diagnosis of TB means that a patient has TB. But what type of TB? It is important to answer this question before starting treatment. A case definition tells us the type of TB. We define TB cases in a standardised way. This means that when we talk about a certain type of TB, we are all talking about the same thing.

PRACTICAL POINT

On making the diagnosis of TB, you must also decide on the TB case definition.

7 1 2 Questions and answers about case definitions

Why make case definitions? There are 2 purposes:

- a) to determine treatment;
- b) for recording and reporting (see Chapter 2).

Why do case definitions determine treatment? There are 3 reasons:

- a) to identify priority cases;
- b) to make the most cost-effective use of resources (by targeting resources on priority cases);
- c) to minimise side-effects for patients (by using the most intensive regimens only for certain cases).

What determines a case definition? There are 4 determinants:

- a) site of TB
- b) result of sputum smear
- c) previous TB treatment
- d) severity of TB

PRACTICAL POINT

Always ask a "new" TB patient if he has ever had TB treatment before.

DETERMINANT OF CASE DEFINITION

IMPORTANCE

some authorities recommend a more intensive regimen for certain sites (e.g. pulmonary compared to extrapulmonary) recording and reporting (in a good NTP, at least 50% of total cases will be pulmonary)

side of TB

priority is to identify sputum smear-positive cases (since these are the infectious cases)

recording and reporting (monitoring of bacteriological cure is readily available only in this group)

the previously treated patient who is still sputum smear-positive has a high risk of drug-resistant TB and so needs a different and more powerful regimen

most authorities recommend a more intensive regimen for smear-negative PTB patients with extensive disease rather than limited disease

severity of TB

result of sputum smear for AFBs

previous TB treatment

PRACTICAL POINT
The following are forms of extrapulmonary TB: pleural effusion (pleura are outside the lungs); hilar lymphadenopathy (hilar lymph nodes are outside the lungs); miliary (TB is widespread throughout the body and not limited to the lungs).

7.1.4 Case definitions by previous treatment

New

A patient who for sure has never taken anti-TB drugs for more than one month.

Relapse

A TB patient who
a) previously received treatment and was declared cured **AND**
b) has once again developed sputum smear-positive TB.

Treatment failure

A new TB patient who is still sputum smear-positive 5 months or more after starting treatment.

Return after interruption of treatment (default)

A new TB patient who
a) completed at least one month of treatment **AND**
b) returned after at least 2 months' interruption of treatment

Transfer in

A TB patient already registered for treatment in one district who transfers to another district where he continues treatment.

Other

A TB patient who does not easily fit into one of the above case definitions. One example is a chronic case (a TB patient who remains sputum smear-positive after completing a supervised re-treatment regimen).

7.1.5 Case definitions by site and result of sputum smear

PTB

Smear positive case:

at least 2 sputum smears positive for AFBs **OR**
1 sputum smear positive for AFBs and chest X-ray abnormalities consistent with active TB.

Smear negative case:

at least 2 (and preferably 3) sputum smears negative for AFBs **AND**
chest X-ray abnormalities consistent with active TB. In most cases, the patient will have had treatment with a broad-spectrum antibiotic, with no response.



7 2 STANDARDISED TREATMENT CATEGORIES

Based on case definition, a TB patient falls into 1 of 4 categories for treatment. The categories are in order of priority. The highest priority is to treat Category 1 patients. The lowest priority is to treat Category 4 patients. The table below shows the patients belonging to each category.

TB TREATMENT CATEGORY	PATIENTS
Category 1	new sputum smear-positive PTB newly diagnosed seriously ill patients with severe forms of TB
Category 2	relapse treatment failure return after default
Category 3	sputum smear-negative PTB with limited parenchymal involvement extrapulmonary TB (less severe forms)
Category 4	chronic cases

The table below shows the severe and less severe forms of extrapulmonary TB.

SEVERE EXTRAPULMONARY TB	LESS SEVERE EXTRAPULMONARY TB
<ul style="list-style-type: none">meningitismiliarypericarditisperitonitisbilateral or extensive pleural effusionspinalintestinalgenito-urinary	<ul style="list-style-type: none">lymph nodepleural effusion (unilateral)bone (excluding spine)peripheral jointadrenal gland

Children

Children and adolescents often fall into Category 3. PTB in children is almost always "smear-negative" (actually smear not done, since children rarely cough up sputum). Young people infected during adolescence may develop primary TB. This usually presents as pleural effusion or small parenchymal lesions in the lungs. In one series of adolescents with pleural effusion, without treatment about 25% went on to develop PTB.

SUGGESTED FURTHER READING

WHO. Treatment of tuberculosis. Guidelines for national programmes. GE, 1993.

CHAPTER 8 TREATMENT OF TB PATIENTS

8 1 INTRODUCTION

Aims of anti-TB drug treatment

- To cure the patient of TB.
- To prevent death from active TB or its late effects.
- To prevent TB relapse.
- To decrease TB transmission to others.

PRACTICAL POINT

Properly applied anti-TB drug treatment will achieve these aims and prevent the emergence of drug resistant *M. tuberculosis*.

Effective anti-TB drug treatment = properly applied Short-Course Chemotherapy

We have known for over 100 years that *M. tuberculosis* causes TB. We have had effective anti-TB drugs for nearly 50 years. Yet the world's TB problem is now bigger than ever. Why? The problem is not the lack of an effective treatment. Properly applied short-course chemotherapy (SCC) fulfills the above aims of anti-TB drug treatment. The problem is an organisational problem: how to apply SCC properly? The answer is a properly managed TB control programme. Chapter 2 describes the organisational framework of an effective TB control programme.

Standardised TB treatment regimens

There are many different possible anti-TB treatment regimens. The World Health Organisation (WHO) and the International Union Against Tuberculosis and Lung Disease (IUATLD) recommend standardised TB treatment regimens. The national TB control programme (NTP) in your country will recommend which regimens to use. When properly applied, these standardised regimens fulfill the above aims of anti-TB drug treatment. The regimens are affordable. The World Bank recognises short-course chemotherapy (SCC) as one of the most cost-effective of all health interventions.

The table shows the essential anti-TB drugs and their mode of action, potency, and recommended dose.

ESSENTIAL ANTI-TB DRUG (ABBREVIATION)	MODE OF ACTION	POTENCY	RECOMMENDED DOSE (MG/KG)		
			DAILY	INTERMITTENT	
				3x/wk	2x/wk
isoniazid (H)	bactericidal	high	5	10	15
rifampicin (R)	bactericidal	high	10	10	10
pyrazinamide (Z)	bactericidal	low	25	35	50
streptomycin (S)	bactericidal	low	15	15	15
ethambutol (E)	bacteriostatic	low	15	(30)	(45)
thiacetazone (T)	bacteriostatic	low	3	not applicable	

The available formulations and combinations of these drugs vary from country to country. Follow the recommendations in your NTP manual.

Intermittent use

Thiacetazone is the only anti-TB drug not effective when given intermittently (2 or 3 times a week). The efficacy of intermittent ethambutol is not proven.

8 2 MODES OF ACTION OF ANTI-TB DRUGS

Consider a population of TB bacilli in a TB patient. This population of bacilli consists of the following groups:

- a) metabolically active, continuously growing bacilli inside cavities;
- b) bacilli inside cells, e.g. macrophages;
- c) semi-dormant bacilli (persisters) which undergo occasional spurts of metabolism;
- d) dormant bacilli which fade away and die on their own.

Different anti-TB drugs act against different groups of bacilli.

PRACTICAL POINT

Anti-TB drug treatment is so long because it is difficult to kill the semi-dormant TB bacilli.



ISONIAZID kills 90% of the total population of bacilli during the first few days of treatment. It is most effective against the metabolically active, continuously growing bacilli.

RIFAMPICIN can kill the semi-dormant bacilli which isoniazid cannot.

PYRAZINAMIDE kills bacilli in an acid environment inside cells, e.g. macrophages.

Sterilising action

This means killing all the bacilli. The persisters are hardest to kill. The aim of killing all the bacilli is to prevent relapse. Rifampicin is the most effective sterilising drug. Its effectiveness makes short-course chemotherapy possible. Pyrazinamide is also a good sterilising drug, since it kills the bacilli protected inside cells.

Preventing drug resistance

Consider a population of TB bacilli never previously exposed to anti-TB drugs. There will be a few naturally-occurring drug-resistant mutant bacilli. Faced with anti-TB drugs, these drug-resistant mutant bacilli will grow and replace the drug-sensitive bacilli under the following circumstances:

- a) inadequate anti-TB drug combinations;
- b) anti-TB drug treatment not properly applied.

Isoniazid and rifampicin are most effective in preventing resistance to other drugs. Streptomycin and ethambutol are slightly less effective.

8 3 TB TREATMENT REGIMENS

Treatment regimens have an initial (intensive) phase and a continuation phase.

8 3 1 New cases

Initial phase (2 months)

During the initial phase, there is rapid killing of TB bacilli. Infectious patients become non-infectious within about 2 weeks. Symptoms improve. The vast majority of patients with sputum smear-positive TB become sputum smear-negative within 2 months. Directly observed therapy (DOT) is essential in the initial phase to ensure that the patient takes every single



dose. This protects rifampicin against the development of drug resistance. The risk of drug resistance is higher during the early stages of anti-TB drug treatment when there are more TB bacilli.

Continuation phase (4-6 months)

Fewer drugs are necessary, but for a longer time, in the continuation phase. The drugs eliminate the remaining TB bacilli. Killing the persisters prevents relapse after completion of treatment. Directly observed therapy is the ideal when the patient receives rifampicin in the continuation phase. If local conditions do not allow directly observed therapy, the next best is as close supervision as possible, for example weekly supervision. The risk of drug resistance is less during the continuation phase when there are fewer TB bacilli.

The patient usually receives monthly drug supplies for self-administered treatment during a continuation phase which does not include rifampicin.

2 Retreatment cases

The initial phase lasts 3 months, with directly observed therapy. The continuation phase lasts 5 months, with close supervision.

3 Standard code for TB treatment regimens

There is a standard code for TB treatment regimens. Each anti-TB drug has an abbreviation (shown in the table on page 84). A regimen consists of 2 phases. The number before a phase is the duration of that phase in months. A number in subscript (e.g. 3) after a letter is the number of doses of that drug per week. If there is no number in subscript after a letter, then treatment with that drug is daily. An alternative drug (or drugs) appears as a letter (or letters) in brackets.

Example

2 SHRZ / 6 HE. This is a common regimen.

The **initial phase** is **2 SHRZ**. The duration of the phase is 2 months. Drug treatment is daily (no subscript number, e.g. 3 after the letters), with streptomycin (S), isoniazid (H), rifampicin (R) and pyrazinamide (Z).

The **continuation phase** is **6 HE**. The duration of the phase is 6 months. Drug treatment is daily, with isoniazid (H) and ethambutol (E).

2 SHRZ / 4 H₃R₃. In some countries, resources are available to provide

rifampicin in the continuation phase as well as in the initial phase. The intensive phase (**2 SHRZ**) is the same as before.

The continuation phase is **4 H₃R₃**. The duration is 4 months, with isoniazid and rifampicin three times per week (subscript number 3 after the letters).

4 Recommended treatment regimens

There are several different possible regimens. The regimen recommended depends on the patient treatment category (see Chapter 7). The table shows possible alternative regimens for each treatment category. Follow the regimens recommended by your NTP in your country. Look in your NTP manual.

ALTERNATIVE TREATMENT REGIMENS FOR EACH PATIENT TREATMENT CATEGORY

TB TREATMENT CATEGORY	TB PATIENTS	ALTERNATIVE TB TREATMENT REGIMENS	
		INITIAL PHASE	CONTINUATION PHASE
1	new smear-positive PTB seriously ill; extrapulmonary or smear-negative pulmonary (severe TB)	2 SHRZ (EHRZ) 2 SHRZ (EHRZ) 2 SHRZ (EHRZ)	6 HE 4 HR 4 H ₃ R ₃
2	sputum smear-positive: relapse treatment failure return after default	2 SHRZE/1 HRZE 2 SHRZE/1 HRZE	5 H ₃ R ₃ E ₃ 5 HRE
3	smear-negative PTB extrapulmonary TB (less severe)	2 HRZ or 2 H ₃ R ₃ Z ₃ 2 HRZ or 2 H ₃ R ₃ Z ₃ 2 HRZ or 2 H ₃ R ₃ Z ₃	6 HE 2 HR/4 H 2 H ₃ R ₃ /4H
4	chronic cose (still sputum-positive after supervised re-treatment)	NOT APPLICABLE (Refer to specialist centre if second-line drugs available)	

Some authorities recommend a 2-month continuation phase with daily isoniazid and rifampicin (2 HR) for Category 1 patients with the following forms of TB: TB meningitis, miliary TB, spinal TB, and endocarditis.



Streptomycin

- In high TB/HIV prevalence populations, overcrowding is common in TB wards. The high staff workload may result in inadequate sterilisation of needles and syringes used for streptomycin injections. There is a risk of transmission of HIV and other blood-born pathogens between patients.
- Streptomycin injections are very painful in wasted HIV-infected TB patients.
- Many NTPs now recommend the use of ethambutol in place of streptomycin.

Thiacetazone

- Thiacetazone is associated with a high risk of severe, and sometimes fatal, skin reaction in HIV-infected individuals.
- Use ethambutol instead of thiacetazone in patients with known or suspected HIV infection.
- At present some countries do not have the resources to substitute ethambutol for thiacetazone. The most effective treatment available in some countries may still include thiacetazone. Where it is not possible to avoid the use of thiacetazone, it is essential to warn patients about the risk of severe skin reactions. Advise the patient to stop thiacetazone at once and report to a health unit if itching or a skin reaction occurs.

8 4 TB TREATMENT REGIMENS: QUESTIONS AND ANSWERS

Why use 4 drugs in the initial phase?

- There is a high degree of initial resistance in some populations.
- Use of a 3-drug regimen runs the risk of selecting out drug-resistant mutants. This may happen especially in patients with high bacillary loads, e.g. cavitary pulmonary TB.
- A 4-drug regimen decreases the risks of drug resistance, treatment failure, and relapse.

Why use pyrazinamide only in the initial phase?

- Pyrazinamide has its maximum sterilising effect within the first 2 months. There is less benefit from longer use.

Is a 4 month continuation phase possible?

- A 4 month continuation phase is possible with rifampicin throughout (e.g. 2 SHRZ/ 4 HR). This is because isoniazid and rifampicin are



Why not always use regimens containing rifampicin throughout?

- Rifampicin is too expensive for many countries to afford these regimens.

Why is it so important to prevent rifampicin resistance?

- Rifampicin is the most effective anti-TB drug. It is unlikely that a new anti-TB drug will become widely available in the near future. If rifampicin resistance becomes widespread, TB will be effectively untreatable.

How do we prevent rifampicin resistance?

- Bad TB control programmes, lack of supervision of anti-TB treatment, bad prescribing by clinicians, and the use of rifampicin alone generate acquired drug resistance. The best way to prevent rifampicin resistance is to strengthen NTPs and ensure directly observed therapy when and where possible. It is important to use methods of drug administration which avoid the danger of the use of rifampicin alone. These include the use whenever possible of fixed-dose combination tablets and of anti-TB drugs supplied in blister packs.

What is the treatment for multi-drug resistant TB?

- Multi-drug resistant TB arises from failure to deliver anti-TB drug treatment properly. Multi-drug resistance represents NTP failure. In many high TB prevalence countries, second-line drugs are prohibitively expensive and unavailable, e.g. ethionamide, cycloserine, kanamycin, capreomycin. Multi-drug resistant TB is therefore often untreatable.

What should we do when faced with multi-drug resistant TB?

- The cause of the problem is NTP failure. The answer is to devote time, effort and resources to improving the NTP. In some countries, one or two specialist centres may have the specialist expertise and second-line drugs available to treat patients with multi-drug resistant TB.

8 5 USE OF ANTI-TB DRUGS IN SPECIAL SITUATIONS

Pregnancy

- Streptomycin during pregnancy can cause permanent deafness in the baby.
- Do not give streptomycin in pregnancy. Use ethambutol instead.



Renal failure

- Rifampicin, isoniazid and pyrazinamide are safe.
- The excretion of streptomycin is renal. The excretion of ethambutol and thiocetazone is partly renal.
- Avoid streptomycin and ethambutol if there are alternatives. Otherwise give in reduced doses at less frequent intervals.
- Do not give thiocetazone. The margin is too narrow between the therapeutic and toxic dose.

Liver disease

- Most anti-TB drugs can cause liver damage. Jaundiced patients who develop TB should receive treatment with the following regimen: 2 SHE / 6 HE.
- Do not give pyrazinamide to patients with liver disease.

THE ROLE OF ADJUVANT STEROID TREATMENT: QUESTIONS AND ANSWERS

What is adjuvant steroid treatment?

Adjuvant steroid treatment is steroid treatment given in addition to anti-TB drug treatment. Prospective controlled clinical trials have confirmed the benefit of steroids in TB meningitis and pleural and pericardial TB.

What are the indications for treatment with steroids?

- TB meningitis (decreased consciousness, neurological defects, or spinal block).
- TB pericarditis (with effusion or constriction).
- TB pleural effusion (when large with severe symptoms).
- Hypoadrenalism (TB of adrenal glands).
- TB laryngitis (with life-threatening airway obstruction).
- Severe hypersensitivity reactions to anti-TB drugs.
- Renal tract TB (to prevent ureteric scarring).
- Massive lymph node enlargement with pressure effects.

What are the recommended treatment doses of prednisolone?

Rifampicin is a potent inducer of hepatic enzymes which metabolise steroids. The effective dose of prednisolone is therefore half the prescribed treatment dose given to the patient. The table below shows suggested treatment doses of prednisolone.

INDICATION

PREDNISOLONE TREATMENT

TB meningitis	60mg daily for weeks 1-4, then decrease over several weeks
TB pericarditis	60mg daily for weeks 1-4 30mg daily for weeks 5-8 then decrease over several weeks
TB pleural effusion	40mg daily for 1-2 weeks

Is steroid treatment safe in TB/HIV patients?

Steroids are immunosuppressants. The worry is that steroids may further depress immunity and increase risk of opportunistic infections in HIV-positive patients. However, on balance, TB/HIV patients are still likely to benefit from the use of steroids for the above indications.

MONITORING OF TB PATIENTS DURING TREATMENT

Bacteriological monitoring is readily available only for patients with sputum smear-positive pulmonary TB. Routine monitoring of treatment response by chest X-rays is unnecessary and wasteful of resources. For other TB patients, clinical monitoring is the usual guide to treatment response.

PRACTICAL POINT

Recording treatment results in sputum smear-positive pulmonary TB patients is vital to monitor patient cure and NTP effectiveness (see Chapter 2).

Monitoring of patients with sputum smear-positive PTB

WHEN TO MONITOR	8 MONTH TREATMENT REGIMEN	6 MONTH TREATMENT REGIMEN
At time of diagnosis	SPUTUM SMEAR	SPUTUM SMEAR
At end of initial phase	SPUTUM SMEAR	SPUTUM SMEAR
In continuation phase	SPUTUM SMEAR (MONTH5)	SPUTUM SMEAR (MONTH5)
On completion of treatment	SPUTUM SMEAR (MONTH8)	SPUTUM SMEAR (MONTH6)

The vast majority of patients have a negative sputum smear at the end of the initial phase. If the sputum smear is still positive at the end of the initial phase, continue initial phase treatment with the same 4 drugs for 4 more weeks. If you check the sputum smear again at this point, it is unlikely still to be positive. Go on to the continuation phase (even if the sputum smear after the extra 4 weeks of initial phase treatment is still positive).

Sputum smear in continuation phase


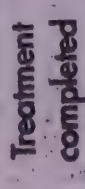
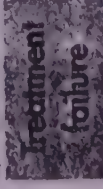


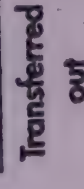
In 8 month regimens, a positive sputum smear at 5 months (or any time after 5 months) means treatment failure. In 6 month regimens, a positive sputum smear at 5 months (or any time after 5 months) means treatment failure. A common cause of treatment failure is the failure of the programme to ensure patient adherence to treatment. The patient changes treatment category to Category 2 and starts the re-treatment regimen.

Sputum smear on completion of treatment

In 8 month regimens, negative sputum smears at 5 and at 7 or 8 months mean bacteriological cure. In 6 month regimens, negative sputum smears at 5 and 6 months mean bacteriological cure.

8 7 2 Recording treatment outcome in sputum smear-positive patients

At the end of the treatment course in each individual patient, the District TB Officer should record the treatment outcome as follows:

 Cure	patient who is smear negative at (or one month prior to) the completion of treatment and on at least one previous occasion
 Treatment completed	patient who has completed treatment but in whom smear results are not available on at least two occasions prior to the completion of treatment
 Treatment failure	patient who remains or becomes again smear positive at 5 months or later, after starting treatment
 Died	patient who dies for any reason during the course of chemotherapy
 Defaulted (treatment interrupted)	patient whose treatment has been interrupted for more than 2 consecutive months before the end of course of treatment
 Transferred out	patient who has been transferred to another treatment centre and whose treatment results are not known



What is cohort analysis?

A cohort of TB patients consists of all those sputum smear-positive PTB patients registered during a certain time. The time period may be a quarter of a year or one year. For example, consider all those sputum smear-positive PTB patients registered from 1 January to 31 March in any year. They form a cohort for that quarter-year. Cohort analysis refers to the statistical breakdown of that cohort according to certain indicators. These indicators are the standardised case definitions and treatment categories (see Chapter 7) and the 6 treatment outcomes shown above.

Who performs cohort analysis and how often?

Cohort analysis is a continuous process. The District TB Officer performs cohort analysis on TB patients registered in his district every quarter-year and at the end of every year. The Regional TB Officer performs cohort analysis on all TB patients registered in the region. The NTP directorate performs cohort analysis on all TB patients registered nationally.

What is cohort analysis for?

Cohort analysis is the key management tool used to evaluate the effectiveness of TB control programme delivery. It enables regional NTP staff and the NTP directorate to identify districts with problems. Examples of problems identified include the following: low cure rate, high default rate, higher than expected proportions of sputum smear-negative PTB or extrapulmonary TB, lower than expected case detection rate. Identification of problems enables the NTP to overcome them and improve programme delivery.

8 8 RESPONSE OF HIV-POSITIVE TB PATIENTS TO ANTI-TB TREATMENT

Mortality

The mortality of TB/HIV patients 1 year after starting TB treatment is about 20%. This mortality is greater than the mortality in HIV-negative TB patients. The excess mortality in TB/HIV patients during and after treatment is partly due to TB itself and partly due to other HIV-related problems. These other HIV-related problems include the following: septicaemia, diarrhoea, pneumonia, anaemia, Kaposi's sarcoma, cryptococcal meningitis.

Mortality is less in TB/HIV patients treated with SCC than with the old standard regimen (1 SHT or SHE / 11 HT or HE). This is partly because SCC is a more effective anti-TB treatment. Also, rifampicin has broad-



spectrum antimicrobial activity as well as anti-TB activity. This may decrease mortality due to HIV-related bacterial infections during anti-TB treatment.

Response in survivors

Several studies have assessed the clinical, radiological, and microbiological response to SCC in HIV-positive and HIV-negative TB patients. Excluding patients who died, response rates were similar in HIV-positive and HIV-negative TB patients. The only exception was that on average weight gain was less in HIV-positive than in HIV-negative TB patients.

RECURRENCE OF TB AFTER COMPLETING ANTI-TB TREATMENT

Old standard treatment

The recurrence rate is higher in HIV-positive than in HIV-negative TB patients. In one study of TB/HIV patients there was an association between recurrence and cutaneous reaction to thiacectazone. A severe thiacectazone reaction necessitated interruption of treatment and a change to ethambutol. There are several possible explanations for the link between increased risk of recurrence and thiacectazone reaction. These include treatment interruption, subsequent poor compliance, more advanced immunocompromise, and change to the combination of isoniazid and ethambutol in the 11 months continuation phase.

SCC

The recurrence rate is similar in HIV-positive and HIV-negative TB patients who complete treatment

Recurrence: relapse or re-infection?

When TB recurs after previous cure, there are 2 possibilities:
a) true relapse (reactivation of persisters not killed by anti-TB drugs);
b) re-infection (due to re-exposure to another source of infection).
The proportions of recurrences due to these 2 possibilities are not known.

SUGGESTIONS FOR FURTHER READING

WHO. *Treatment of tuberculosis. Guidelines for national programmes*. Geneva: WHO, 1993.

WHO. *Tuberculosis control workshop report*, Geneva, October 1995, and *Revision of "Treatment of Tuberculosis: Guidelines for National Programmes"*. Geneva: WHO, 1996.

Horne NW. *Modern drug treatment of tuberculosis*. Chest, Heart and Stroke Association. 7th edition. London, 1990.

Dean P, Ebrahim GJ. *The practical care of sick children. A manual for use in small tropical hospitals*. London: Macmillan, 1984.

CHAPTER 9 SIDE EFFECTS OF ANTI-TB DRUGS

9 1 INTRODUCTION

Most TB patients complete their treatment without any significant drug side effects. However, a few patients do develop side effects. So clinical monitoring of all TB patients for side effects is important during TB treatment. Routine laboratory monitoring is not necessary.

How do health personnel monitor patients for drug side effects?

- a) by teaching patients how to recognise symptoms of common side effects and to report if they develop such symptoms.
- b) by asking specifically about these symptoms when they see all patients at least monthly during treatment.

9 2 PREVENTION OF SIDE EFFECTS

Health personnel should be aware of the special situations which influence the choice and dose of anti-TB drugs (see Chapter 8).

It is possible to prevent the peripheral neuropathy caused by isoniazid. This neuropathy usually shows as a burning sensation of the feet. It occurs more commonly in HIV-positive individuals and in drinkers (alcohol). These patients should receive preventive treatment with pyridoxine 10 mg daily. Ideally, where possible, pyridoxine 10 mg daily should routinely accompany isoniazid.

9 3 WHERE TO MANAGE DRUG REACTIONS

REACTION	WHERE TO MANAGE REACTION
minor, e.g. gastro-intestinal joint pains	out-patient setting
major, e.g. jaundice severe rash	refer to district or central hospital

9 4 WHEN TO STOP ANTI-TB DRUGS

When a patient has minor drug side-effects, explain the situation, offer symptomatic treatment, and advise the patient to return for further assessment if the side-effects persist or worsen.

responsible at once. If a patient develops one of the following reactions, he must never receive that drug again:

REACTION	DRUG RESPONSIBLE
severe rash, agranulocytosis	thiacetazone
hearing loss or disturbed balance	streptomycin
visual disturbance (poor vision and colour perception)	ethambutol
renal failure, shock, or thrombocytopenia	rifampicin

9 5 SIDE EFFECTS OF ANTI-TB DRUGS

DRUG	COMMON SIDE EFFECTS	RARE SIDE EFFECTS
isoniazid	<ul style="list-style-type: none">peripheral neuropathyhepatitis	<ul style="list-style-type: none">convulsions, pellaagra, joint pains, agranulocytosis, lupoid reactions, skin rash
rifampicin	<ul style="list-style-type: none">gastrointestinal: anorexia, nausea, vomiting, abdominal painhepatitisreduced effectiveness of oral contraceptive pill	<ul style="list-style-type: none">acute renal failure, shock, thrombocytopenia, skin rash, "flu syndrome" (intermittent doses), pseudomembranous colitis, pseudoadrenal crisis
pyrazinamide	<ul style="list-style-type: none">joint painshepatitis	<ul style="list-style-type: none">gastrointestinal symptoms, skin rash, sideroblastic anaemia
streptomycin	<ul style="list-style-type: none">auditory and vestibular nerve damage (also to foetus)renal damage	<ul style="list-style-type: none">skin rash
ethambutol	<ul style="list-style-type: none">optic neuritis	<ul style="list-style-type: none">skin rash, joint pains, peripheral neuropathy
thiacetazone	<ul style="list-style-type: none">skin rash, often with mucous membrane involvement	<ul style="list-style-type: none">hepatitis, agranulocytosis



contraceptive pill. Advise a woman to use another form of contraception.

9 5 1 Side effects of anti-TB drugs in TB/HIV patients

Adverse drug reactions are more common in HIV-positive than in HIV-negative TB patients. Risk of drug reaction increases with increased immunocompromise. Most reactions occur in the first 2 months of treatment.

Skin rash

This is the commonest reaction. Fever often precedes and accompanies the rash. Mucous membrane involvement is common. The usual drug responsible is thiacetazone. Streptomycin and rifampicin are sometimes to blame. Severe skin reactions, which may be fatal, include exfoliative dermatitis, Stevens-Johnson syndrome and toxic epidermal necrolysis.

Other reactions

The commonest reactions necessitating change in treatment include gastrointestinal disturbance and hepatitis. There may be an increased risk of rifampicin-associated anaphylactic shock and thrombocytopenia.



6 SYMPTOM-BASED APPROACH TO MANAGEMENT OF DRUG SIDE EFFECTS

SIDE EFFECTS	DRUG(S) PROBABLY RESPONSIBLE	MANAGEMENT
minor		continue anti-TB drugs
anorexia, nausea,	rifampicin.	give tablets last thing at night
abdominal pain		
joint pains.	pyrazinamide.	aspirin
burning sensation in feet	isoniazid	pyridoxine 100 mg daily
orange/red urine	rifampicin.	reassurance
major		stop drug(s) responsible
skin itching/ rash	thiacetazone.	stop anti-TB drugs (see below) (streptomycin)
deafness.	streptomycin.	stop streptomycin, ethambutol instead
(no wax on otoscopy)		
dizziness.	streptomycin.	stop streptomycin, use ethambutol instead
(vertigo and nystogimus)		
jaundice.	most anti-TB drugs	stop all anti-TB drugs until (other causes excluded) jaundice resolves (see below)
vomiting and confusion	most anti-TB drugs	stop anti-TB drugs, urgent liver function tests (suspected drug-induced pre-icteric hepatitis)
visual impairment	ethambutol.	stop ethambutol
generalised, including shock and purpura	rifampicin.	stop rifampicin

7 MANAGEMENT OF SKIN ITCHING/RASH

The approach depends on whether or not the patient is receiving thiacetazone. In populations with a high TB/HIV prevalence, thiacetazone is the drug most likely to cause skin reactions.

7.1 Treatment regimen includes thiacetazone

If a patient starts to itch, and there is no other obvious cause (e.g. scabies), stop the anti-TB drugs at once. The itching may be a warning sign of severe skin reaction. Stopping the thiacetazone at once may avert, or decrease the severity, of the skin reaction.

- Give the patient intravenous fluids if the skin reaction is severe:
- a) exfoliative dermatitis or toxic epidermal necrolysis
- b) mucous membrane involvement
- c) hypotension

Many physicians give steroid treatment, although there is no firm evidence that this helps. A typical dose schedule consists of 60 mg daily of oral prednisolone until there is some improvement. A gradual reduction in dose over the next few days depends on the patient's response. Initially, if a patient is unable to swallow, give intravenous hydrocortisone 100-200 mg daily (instead of oral prednisolone). On recovery, restart anti-TB drugs, replacing thiacetazone with ethambutol.

PRACTICAL POINT
Never give a patient thiacetazone again after any thiacetazone reaction.

A severe reaction may mean stopping anti-TB treatment for 3-4 weeks. A severely ill TB patient may die without anti-TB treatment. In this case, give him 2 or more previously unused drugs until the reaction has resolved. Then reintroduce the initial regimen (with ethambutol instead of thiacetazone).

7.2 Treatment regimen does not include thiacetazone

If a patient starts to itch, exclude other obvious causes. Try treatment with anti-histamines, continue anti-TB treatment and observe the patient closely. In some cases, the itching resolves. In other cases, a rash develops. In this case, stop the anti-TB drugs. Wait for the rash to resolve. If the reaction is severe, the patient may need supportive treatment as above.

The problem now is re-introducing TB treatment when we don't know which anti-TB drug was the drug responsible for the reaction. The table shows the standard approach to re-introducing anti-TB drugs after a drug reaction.

LIKELIHOOD OF CAUSING A REACTION		CHALLENGE DOSES		
DRUG		DAY 1	DAY 2	DAY 3
Isoniazid	least likely	50mg	300mg	300mg
Rifampicin		75mg	300mg	Full dose
Pyrazinamide		250mg	1 gram	Full dose
Ethambutol		100 mg	500mg	Full dose
Streptomycin	most likely	125mg	500mg	Full dose

If possible, while the patient undergoes drug challenging, give him 2 anti-TB drugs which he has not had before. The idea of drug challenging is to identify the drug responsible for the reaction. Drug challenge starts with the anti-TB drug least likely to be responsible for the reaction (i.e. isoniazid). Start with a small challenge dose. If a reaction occurs to a small challenge dose, it will not be such a bad reaction as to a full dose. Gradually increase the dose over 3 days. Repeat the procedure, adding in one drug at a time. A reaction after adding in a particular drug identifies that drug as the one responsible for the reaction.

If the drug responsible for the reaction is pyrazinamide, ethambutol, or streptomycin, resume anti-TB treatment without the offending drug. If possible, replace the offending drug with another drug. It may be necessary to extend the treatment regimen. Consider the start of the resumed regimen as a new start of treatment. This prolongs the total time of TB treatment, but decreases the risk of recurrence.

PRACTICAL POINT

Refer patients with severe drug reactions to specialist centres.

DESENSITISATION

Rarely, patients develop hypersensitivity reactions to the 2 most potent anti-TB drugs, isoniazid and rifampicin. These drugs form the cornerstone of SCC. If an HIV-negative patient has had a reaction (but not a severe reaction) to isoniazid or rifampicin, it may be possible to desensitise the patient to the drug. However, never attempt desensitisation in TB/HIV patients because of the high risk of serious toxicity.

The following method for desensitisation is for reference only, since it applies to HIV-negative TB patients, but not to TB/HIV patients. Start desensitisation with a tenth of the normal dose. Then increase the dose by a tenth each day, until the patient has the full dose on the tenth day. Once drug sensitisation is over, give the drug as part of the usual treatment regimen. If possible, while carrying out desensitisation, give the patient 2 anti-TB drugs which he has not had before. This is to avoid the risk of drug resistance developing during desensitisation.

PRACTICAL POINT

Never attempt desensitisation in TB/HIV patients.

MANAGEMENT OF HEPATITIS

Most anti-TB drugs can damage the liver. Isoniazid and pyrazinamide are most commonly responsible. Ethambutol is rarely responsible. When a patient develops hepatitis during anti-TB treatment, the cause may be the anti-TB treatment or another cause. It is often difficult to find out. Try to rule out other possible causes before deciding that the hepatitis is drug-induced. Hepatitis presents with anorexia, jaundice and often liver enlargement.

If you diagnose drug-induced hepatitis, stop the anti-TB drugs. Wait until the jaundice resolves. It is strange, but fortunate, that in most cases the patient can re-start the same anti-TB drugs without hepatitis returning. A severely ill TB patient may die without anti-TB drugs. In this case, treat the patient with 2 of the least hepatotoxic drugs, streptomycin and ethambutol. When the hepatitis resolves, re-start usual anti TB treatment



SUGGESTIONS FOR FURTHER READING

Crofton J. Horne N and Miller F. *Clinical Tuberculosis*. The MacMillan Press limited. 1992.

Horne NW. *Modern Drug Treatment of Tuberculosis*. The Chest, Heart and Stroke Association. Seventh edition. London, 1990.



CHAPTER 10 MANAGEMENT OF OTHER HIV-RELATED DISEASES IN TB/HIV PATIENTS

10 1 INTRODUCTION

TB/HIV patients may have other HIV-related diseases. This chapter is a brief guide to their management at district hospital level. Therapies in "bold" are available in most district hospitals. See the WHO guidelines "Clinical management of HIV infection" and "Management of sexually transmitted diseases" for a more complete account.

(Note that references to trimethoprim-sulfamethoxazole (TMP-SMX) are to the standard strength tablet, which contains 80mg of trimethoprim and 400mg of sulfamethoxazole).

10 2 SEXUALLY TRANSMITTED DISEASES

A person who has un-safe sex is at risk of several sexually transmitted diseases (STDs). So a patient with one STD is at increased risk of having another STD. HIV is usually sexually transmitted. STDs other than HIV are common in TB/HIV patients. This chapter gives a brief account of the drug treatment of STDs. When you treat a patient with STD, also remember patient education, counselling, condom provision and partner management.

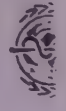
10 2 1 Syndromic management

Accurate STD diagnosis is often not feasible. WHO has developed a "syndromic management". This is based on the recognition of consistent groups of symptoms and signs (syndromes). The treatment recommended for each syndrome cures the majority of infections responsible for causing each syndrome. The table shows the recommended plans of treatment for the common STD-associated syndromes where laboratory investigations are not available.

PLAN OF TREATMENT	
SYNDROME	
urethral discharge	treat for gonorrhoea and chlamydia
cervicitis	treat for uncomplicated gonorrhoea and chlamydia
vaginitis	treat for candidiasis and Trichomonas vaginalis/ bacterial vaginosis
vaginal discharge	treat for cervicitis and vaginitis
	treat for syphilis and chancroid
	treat for syphilis and chancroid
	treat for lymphogranuloma venereum
MEN AND WOMEN	
genital ulcers	
inguinal bubo	
-with ulcers	
-without ulcers	
10 2 2	Treatment regimens for common STDs

The table shows treatment regimens for the common STDs.
Do not use ciprofloxacin or tetracyclines in pregnancy or in childhood.

STD	TREATMENT REGIMEN
gonorrhoea (uncomplicated)	ciprofloxacin 500mg orally as a single dose OR ceftriaxone 250mg by i.m. injection as a single dose OR cefixime 400mg orally as a single dose OR spectinomycin 2g by i.m. injection as a single dose OR trimethoprim (80mg)/sulfamethoxazole (400mg) (TMP-SMX) 10 tablets orally as a single dose OR gentamicin 240mg by i.m. injection as a single dose
chlamydia	doxycycline 100mg orally 2x daily for 7 days OR tetracycline 500mg orally 4x daily for 7 days OR erythromycin 500mg orally 4x daily for 7 days
primary syphilis (chancres)	benzathine penicillin G 2.4 million IU, by i.m. injection at a single session (often split into 2 doses at separate sites) OR procaine penicillin G 1.2 million IU daily by i.m. injection for 10 consecutive days OR (if allergic to penicillin) tetracycline 500mg orally 4x daily for 15 days OR doxycycline 100mg orally 2x daily for 15 days OR erythromycin 500mg 4x daily for 15 days



lymphogranuloma venereum	ciprofloxacin 500mg orally as a single dose OR ceftriaxone 250mg by i.m. injection as a single dose OR spectinomycin 2g by i.m. injection as a single dose OR TMP-SMX 2 tablets orally 2x daily for 7 days
	doxycycline 100mg orally 2x daily for 14 days OR tetracycline 500mg orally 4x daily for 14 days OR erythromycin 500mg orally daily for 14 days OR sulfadiazine 1g orally 4x daily for 14 days
candidiasis	nystatin 100,000IU intravaginally once daily for 14 days OR miconazole or clotrimazole 200mg intravaginally once daily for 3 days OR clotrimazole 500mg intravaginally as a single dose
Trichomonas vaginalis	metronidazole 2g orally as a single dose OR metronidazole 400-500mg orally 2x daily for 7 days
bacterial vaginosis	metronidazole 2g orally as a single dose OR metronidazole 400-500mg orally 2x daily for 7 days
10 3	SKIN AND MOUTH PROBLEMS

The diagnosis of these HIV-related skin and mouth problems usually rests on characteristic clinical features. The tables show diagnoses and treatments.

DIAGNOSIS	TREATMENT
SKIN PROBLEMS	
• VIRUS INFECTIONS	
Herpes simplex (oral and genital)	Local lesion care. Acyclovir 200 mg five times daily until healed.
Varicella zoster	Local lesion care. Acyclovir 800 mg po 5x/day for at least 7 days.
Anal/genital warts (human papilloma virus)	Topical 20% podophyllin 1-2 times per week until cleared. Trichloroacetic acid. Cryotherapy.



Molluscum contagiosum

Leave the lesions alone OR
Prick each lesion with a needle or sharpened
orange stick and touch with phenol.

• FUNGAL INFECTIONS

Tinea

(pedis/corporis/cruis)

Whitfield's ointment or Castellani's paint
Topical antifungals.
1% Clotrimazole.
2% Miconazole.

In resistant cases use griseofulvin 500 mg 2x daily.

Candidiasis

Local application of 1% aqueous gentian violet
or nystatin ointment 2 x daily until lesions are
cleared.
Topical antifungals.

Cutaneous cryptococcosis/
histoplasmosis

Systemic antifungal therapy.

• BACTERIAL INFECTIONS

Popular folliculitis
(pruritic poplar
dermatosis)

Calamine lotion.
Antihistamines.
Topical antifungals combined with 1%
hydrocortisone.
Strong topical corticosteroids.

Impetigo, furunculosis

Penicillin V 500 mg orally OR
Flucloxacillin or erythromycin 500 mg orally
4 x daily for 1 - 2 weeks

Surgical drainage plus antibiotics (as for impetigo)

Pyomyositis

• OTHER

Seborrhoeic dermatitis

Antifungal shampoos OR topical antifungals with
steroids OR topical 1% hydrocortisone.
Strong topical corticosteroids.

Psoriasis

Conventional antipsoriasis treatment, eg coal
tar in salicylate ointment 2 x daily.

Scabies

Topical benzyl benzoate 25%

Kaposi's Sarcoma

Local lesion care.
Radiotherapy, chemotherapy.

10 4 MOUTH PROBLEMS

Oral candidiasis

Topical antifungals such as amphotericin
lozenges, nystatin pastilles/pessaries:
nystatin drops 100,000 units 3 x daily OR
nystatin pessaries one every 4 hours OR
nystatin tabs 500,000 units 4 x daily.
In resistant cases oral ketoconazole 200 mg
2 x daily.

In all cases treat for 7 - 14 days.

Recurrence is common without prophylaxis.

Hairy leukoplakia

No treatment.

Angular cheilitis

Topical antifungals eg 1% clotrimazole.

Gingivitis /
dental abscesses

Oral metronidazole 400 mg 3 x daily and/or
penicillin V 500 mg 4 x daily for 7 days.

Aphthous ulcers

Mouth rinses with steroid and tetracycline.
Topical corticosteroids.
Oral prednisolone.
Oral acyclovir.
(Oral thalidomide in refractory cases).

10 4 GASTROINTESTINAL PROBLEMS

10 4 1 Dysphagia

There are various HIV-related causes of oesophageal inflammation.
They present in a similar way with pain on swallowing. Oesophageal
candidiasis is the commonest HIV-related cause of dysphagia. The
diagnosis of the other causes needs endoscopy, biopsy and a good
laboratory.

Where there are no facilities for investigation of a known HIV-positive
patient with dysphagia, treat empirically with an oral anti-fungal agent.
Where available, barium swallow shows characteristic appearances of
fine mucosal ulceration. Upper gastrointestinal endoscopy shows white
plaques and biopsy allows confirmation.

The table shows the treatment of the causes of dysphagia.

CAUSE OF DYSPHAGIA	TREATMENT
<i>Candida oesophagitis</i>	Nystatin 500,000 units 4 x daily. Nystatin pessaries 100,000 units every 4 hours. Ketoconazole 200 mg twice daily OR fluconazole 100 mg od. (All medications taken for 1-14 days). Prophylaxis with nystatin pastilles OR fluconazole 100 mg daily for life
Herpes simplex	Acyclovir 800 mg po five times daily for 7-10 days.
Cytomegalovirus	Treatment usually not available and too expensive (intravenous gancyclovir).
Ulcers of unknown cause	Prednisolone 40 mg daily for 2 weeks, then slowly taper to zero.

10 4 2 Diarrhoea

Introduction

Chronic diarrhoea is very common, affecting up to 60% of HIV-positive individuals at some time in their illness. Common accompanying features include the following: nausea, vomiting, abdominal cramps, flatulence, weight loss and dehydration.

Rehydration

Always assess the state of hydration of any patient with diarrhoea. Most patients with mild to moderate dehydration will receive oral rehydration solution. A few patients, with severe dehydration, need intravenous fluids.

Investigation

Where facilities are available, send multiple stool samples for microscopy and culture. With appropriate stains it is possible on microscopy to diagnose the following pathogens: *Cryptosporidium*, *Isospora belli*, *Microsporidia*. Stool culture can enable the diagnosis of *Salmonella*, *Shigella*, *Clostridium difficile*.

Treatment

In most cases, the cause is not known. So treatment in these cases is empirical. Some cases (probably due to *Isospora belli*) respond to



treatment with trimethoprim-sulfamethoxazole (probably due to *Microsporidia*) respond to treatment with metronidazole. Sometimes you do find a specific cause of diarrhoea. The table shows specific causes with the appropriate treatment.

DIAGNOSIS	TREATMENT
BACTERIAL INFECTIONS	
<i>Salmonella</i>	TMP-SMX 2 tablets 2x daily for 7 days OR chloramphenicol 500 mg 4x daily for 7 days.
<i>Shigella</i>	TMP-SMX 2 tablets 2x daily for 7 days OR nalidixic acid 1g 4x daily for 5 days
<i>Clostridium difficile</i>	metronidazole 400 mg 3x daily for 7 days.
PROTOZOAL INFECTIONS	
<i>Cryptosporidium</i>	symptomatic treatment only
<i>Isospora belli</i>	TMP-SMX 2 tablets 2x daily for 7 days
<i>microsporidia</i>	metronidazole 400 mg 3x daily for 7 days

Persistent diarrhoea

Give symptomatic treatment if diarrhoea persists, the cause is not known, and there is no response to TMP-SMX then metronidazole. Anti-diarrhoeal agents for symptomatic treatment include codeine and loperamide

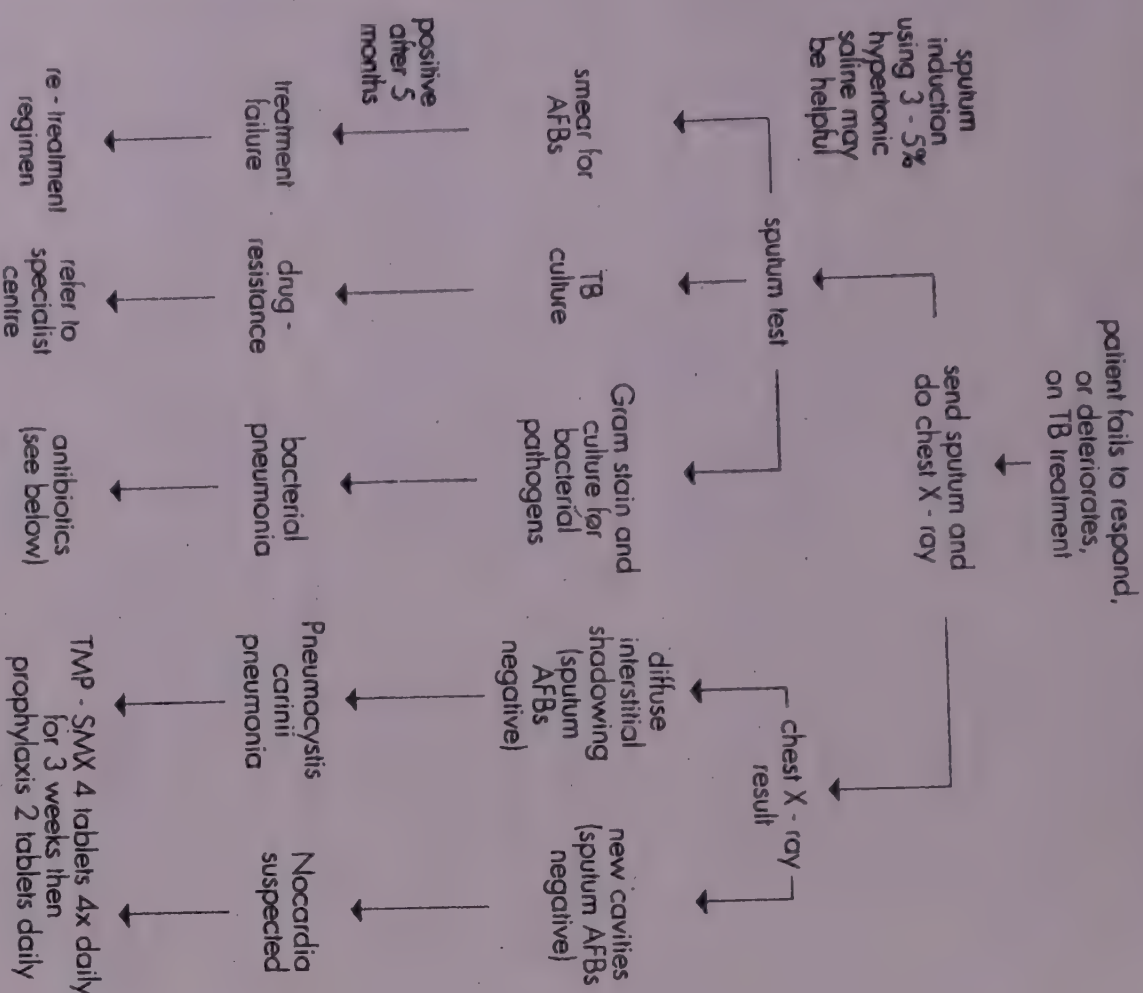
10 5 RESPIRATORY PROBLEMS

Some TB/HIV patients fail to improve, or even deteriorate, during anti-TB treatment. They continue to have, or develop new, respiratory problems, e.g. cough, breathlessness, chest pain. First check that the patient has really been taking his anti-TB drugs. Then consider the following possibilities:

ORIGINAL DIAGNOSIS	POSSIBILITIES
sputum smear-negative PTB . . .	incorrect diagnosis e.g. other pathogens, heart failure, chronic obstructive airways disease
sputum smear-positive PTB . . .	patient not adherent to anti-TB treatment, drug-resistant TB, super-imposed infection with other pathogens.



The flow chart shows the management approach in HIV-positive PTB patients who fail to respond or deteriorate while on anti-TB treatment



The table below shows the main bacterial pathogens responsible for superimposed pneumonia in smear-positive PTB patients and the treatment.

PATHOGEN	TREATMENT
Streptococcus pneumoniae	penicillin or TMP-SMX
Haemophilus influenzae	amoxycillin or TMP-SMX
Staphylococcus aureus	flucloxacillin or chloramphenicol
Gram-negative bacilli	chloramphenicol (and gentamicin if necessary)

10 6 NEUROLOGICAL PROBLEMS

A wide variety of neurological problems may occur in TB/HIV patients.

The common presentations are the following:

- acute confusion
- chronic behaviour change
- persistent headache
- difficulty in walking
- poor vision
- burning sensation in the feet

Neurological problems by reputation are difficult to diagnose. In fact, they are no more difficult to diagnose than other problems, **provided that you take time and care**. You have to take time and care to obtain a detailed history and perform a proper neurological examination. It is usually necessary to obtain some, if not all, of the history from the patient's relatives or friends. Some simple distich-level laboratory tests on blood and cerebrospinal fluid (CSF) are often helpful.

10 6 1 Acute confusion

The differential diagnosis when a TB/HIV patient becomes acutely confused includes the following:

- acute superimposed infection, e.g. septicaemia, meningitis, malaria;
- hypoxaemia, e.g. pneumothorax, pneumonia, heart failure, anaemia;
- metabolic disturbance, e.g. secondary to diarrhoea, hypoadrenalism;
- adverse drug reaction, e.g. acute confusion may be the first sign of drug-induced acute fulminant liver failure (a useful test, if available, is the prothrombin time).

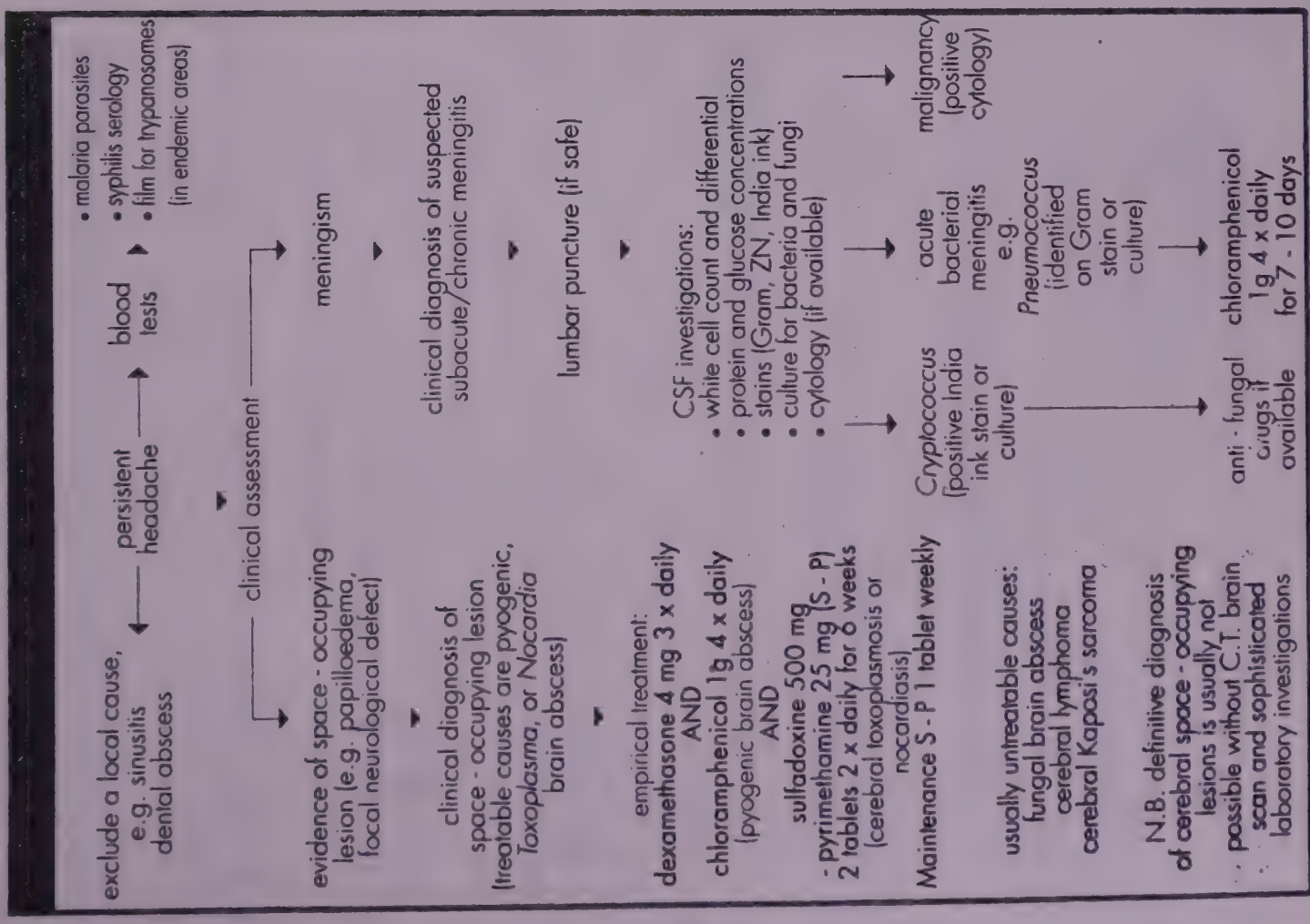
Always check a blood film for malaria. Do a lumbar puncture if the patient has meningism and it is safe to do a lumbar puncture. Other investigations depend on the laboratory facilities available and clinical clues to the diagnosis.

10 6 2 Chronic behaviour change

Chronic behaviour change, i.e. over a period of months, is usually due to AIDS dementia or progressive multi-focal leucoencephalopathy. These are untreatable. Since the diagnoses are clinical, you must rule out other treatable possibilities. Send blood for syphilis serology and (in endemic areas) microscopy for trypanosomes. If lumbar puncture is safe, send CSF to the laboratory to exclude chronic meningitis (e.g. cryptococcal, TB).



The flow chart below shows the management approach to the TB/HIV patient with headache. The following features may accompany headache: reduced level of consciousness, confusion, convulsions.



It is possible, but rare, for TB meningitis to develop after a TB patient has already started anti-TB treatment. For example, a cerebral tuberculoma could rupture into the subarachnoid space releasing TB bacilli not yet killed by anti-TB drugs. A commonly recommended treatment regimen for TB meningitis is as follows: 2 SHRZ, 7 HR.

It is unlikely, but possible, that a patient already on TB treatment could develop acute bacterial meningitis. The diagnosis rests on CSF examination.

Cryptococcal meningitis

The outcome is fatal without treatment and often very poor with treatment. In many countries the drugs for treating cryptococcal meningitis are prohibitively expensive in most cases. The treatment for most patients is therefore symptomatic with analgesia and sedation. For those patients, who can afford specific anti-fungal drug treatment, they should receive fluconazole 400 mg daily initially for 10 weeks. An alternative is intravenous amphotericin B (0.5 mg/kg/day) for 6 weeks. Life-long maintenance treatment with fluconazole 200 mg daily is then necessary to prevent relapse.

1064 Difficulty in walking

Spinal TB may cause difficulty in walking. So first make sure (by clinical examination and spine X-ray) that the patient does not also have spinal TB.

The cause of difficulty walking in a TB/HIV patient may be HIV-related (spinal cord myelopathy and occasionally peripheral neuropathy) or unrelated to HIV. A patient with difficulty walking and HIV myelopathy usually has a spastic paraparesis. It is only possible to make this diagnosis by excluding the causes of spinal cord disease unrelated to HIV. The table below shows these main causes of spinal cord disease unrelated to HIV, and the diagnostic tests. In HIV-related peripheral neuropathy, sensory disturbance tends to predominate over motor weakness.

CAUSE OF SPINAL CORD DISEASE	DIAGNOSTIC TESTS
cervical spondylosis	cervical spine X-ray, myelography
prolapsed intervertebral disc	myelography
epidural abscess	myelography
treatable tumours	myelography
(neurofibroma, meningioma)	



schistosomiasis identification of eggs in stool, urine, or rectal snips

neurosyphilis myelography

subacute combined syphilis serology, CSF findings

degeneration of the cord anaemia with raised MCV, low serum vitamin B12 level

Spinal cord schistosomiasis is difficult to diagnose, but schistosomiasis is easy to treat. Consider a patient with a spinal cord problem who lives in an area endemic for schistosomiasis. Give empirical treatment with a stool dose of praziquantel (40 mg/kg) while pursuing further management.

10 6 5 Poor vision

PRACTICAL POINT

If a patient receiving ethambutol develops difficulty seeing clearly, or has problems perceiving colours, stop ethambutol.

Cytomegalovirus retinitis can cause poor vision but is rare in African AIDS patients. The diagnosis rests on the characteristic appearance on fundoscopy of a necrotising retinitis with perivascular haemorrhages and exudates. The treatment with ganciclovir or foscarnet is prohibitively expensive in many countries.

10 6 6 Burning sensation in the feet

HIV may cause a peripheral neuropathy, often worse when a TB patient starts isoniazid. The features which may accompany the painful burning sensation in the feet include distal weakness and atrophy with absent ankle jerks.

Prevention

If resources allow, all TB patients should receive pyridoxine 10 mg daily as prophylaxis against isoniazid neuropathy. Otherwise reserve pyridoxine prophylaxis for HIV-positive TB patients and TB patients who drink alcohol.

Treatment

Treat patients with established isoniazid neuropathy with pyridoxine 100 mg daily. Amitriptyline (25-75 mg at night), phenytoin (100-300 mg at night), or carbamazepine (100-200 mg 2 x daily) may relieve symptoms in HIV neuropathy.

10 7 FEVER

10 7 1 Approach to management

Fever usually settles within 2-3 weeks of starting anti-TB treatment. Further fever may signal a drug reaction or a disseminated infection. The table below shows the approach to management of further or persistent fever.

FEATURES ACCOMPANYING FEVER	LIKELY CAUSE	ACTION
rash	drug reaction	Stop anti-TB drugs
weight loss	disseminated infection	Examine patient
progressive anaemia or pancytopenia		Investigations: <ul style="list-style-type: none">• blood film for malaria• blood cultures• consider lumbar puncture• Start antibiotics for suspected septicæmia

10 7 2 Disseminated infection

Disseminated infection carries a high mortality. The table below shows the wide variety of pathogens which can cause disseminated infection in TB/HIV patients.

PATHOGENS CAUSING DISSEMINATED INFECTION IN TB/HIV PATIENTS

BACTERIA	MYCOBACTERIA	VIRUSES	OTHERS
Salmonella typhimurium	M. avium	Cytomegalo	leishmania
Streptococcus pneumoniae	complex (MAC)	virus	Cryptococcus
Pseudomonas aeruginosa			
Staphylococcus aureus			
Other Gram-negative bacteria			

S. typhimurium and *Pneumococcus* are the commonest identified causes of septicæmia in HIV-positive patients in sub-Saharan Africa. Many strains of *S. typhimurium* are resistant to several antibiotics. If you suspect septicæmia, treat the patient with **chloramphenicol** or **ampicillin** and **gentamicin**.

Disseminated *M. avium* complex (MAC)

This occurs less frequently in AIDS patients in sub-Saharan Africa than elsewhere. Diagnostic facilities and treatment are generally not available in district hospitals and many central hospitals.

10 8 OTHER HIV-RELATED PROBLEMS WHICH MAY OCCUR IN TB/HIV PATIENTS

Tumours KAPOSI'S SARCOMA (KS)

KS can affect many parts of the body, but usually the skin and mouth, and sometimes the lung and pleura, gastrointestinal tract, and pericardium. The clinical appearance is usually distinctive. There is often oedema with KS on the face and legs. Diagnostic confusion can arise with keloids, leprosy, sarcoidosis, and melanoma. In case of doubt, a biopsy is diagnostic. Histology shows typical proliferation of spindle cells and small blood vessels.

Consider a TB/HIV patient with KS. Development of a pleural effusion or progressive lung infiltrations during anti-TB treatment is probably due to KS.

Many countries have limited resources for treating KS. Treatment is often unsatisfactory. Non-steroidal anti-inflammatory drugs (NSAIDs) may help relieve pain. Cytotoxic chemotherapy and radiotherapy may be available in some central hospitals.

. LYMPHOMA

AIDS patients are at increased risk of developing atypical, aggressive lymphomas. Prognosis is poor even with cytotoxic chemotherapy.

Anaemia

Anaemia in TB/HIV patients may be due to any of the following: TB, HIV-induced marrow suppression, concurrent infections, drug side-effects. Treatment is supportive: iron and folic acid; blood transfusion if essential.



The main causes are HIV-induced autoimmune thrombocytopenia and drug side-effects. High-dose steroids may help if there is bleeding and the platelet count is low (less than $20 \times 10^9 / l$).

Renal disease

HIV-related nephropathy causes nephrotic syndrome and progressive renal damage. There is no specific treatment. Treat urinary tract infections in the usual way.

Congestive cardiomyopathy

Consider HIV-related congestive cardiomyopathy in the differential diagnosis of heart failure. Treat heart failure in the usual way.

Arthropathy

Pyrazinamide often causes joint pains but rarely arthritis. HIV-related arthropathy usually affects small joints. NSAIDs may help relieve pain.

Hypoadrenalism

Cytomegalovirus can cause necrotising adrenitis. This is difficult to distinguish from TB of the adrenal glands or pseudoadrenal crisis (rifampicin). Treatment is with steroid supplements.

SUGGESTIONS FOR FURTHER READING

- WHO Global Programme on AIDS. Guidelines for the clinical management of HIV infection in adults. Geneva, 1991.
- WHO Global Programme on AIDS. Guidelines for the clinical management of HIV infection in children. Geneva, 1993.
- WHO Global Programme on AIDS. AIDS in Africa: a manual for physicians. Geneva, 1992.
- WHO Global Programme on AIDS. AIDS home care handbook. Geneva, 1993.
- WHO Global Programme on AIDS. Management of sexually transmitted diseases. Geneva, 1994.
- Maher D, Mwandumba H. Cryptococcal meningitis in Lilongwe and Blantyre, Malawi. *J Infect* 1994, 24: 82-83



CHAPTER 11 COORDINATED CARE IN DIFFERENT SETTINGS

11.1 INTRODUCTION

TB/HIV patients may receive care in different settings. These settings include the patient's home, local health centre, district hospital, and tertiary referral hospital. Coordination of care in different settings promotes continuity of care for the patient.

In the case of TB/HIV patients, sometimes the patient knows that he is HIV-positive and later on develops TB. More often, he only finds out that he is HIV-positive after he has developed TB. In either case, the TB control programme needs to collaborate closely with other services providing support and care for HIV-positive individuals. The clinician who treats the TB/HIV patient is in a key position to refer the patient to appropriate services.

11.2 BENEFITS OF SUPPORT FROM LOCAL HIV/AIDS CARE SERVICES

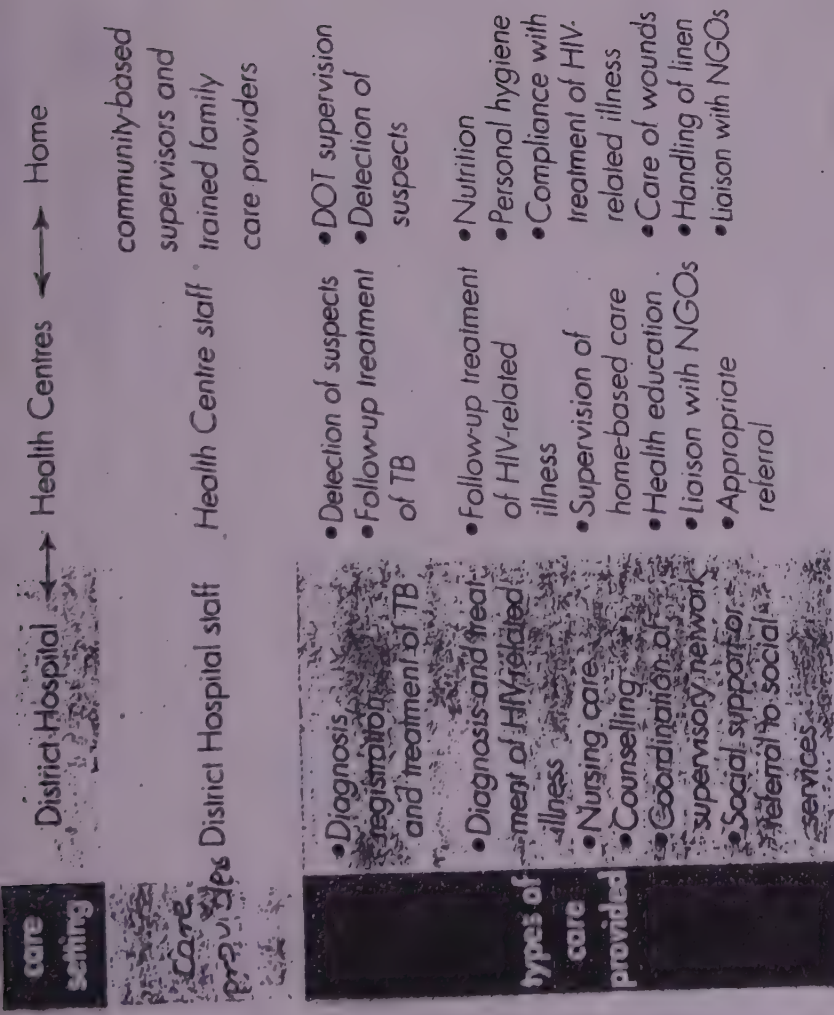
The HIV/AIDS care services available vary from place to place. They include HIV/AIDS community support groups and HIV/AIDS home care schemes. The TB/HIV patient may gain the following benefits from the support of local HIV/AIDS services:

- a) emotional support;
- b) early identification of any new infections;
- c) symptomatic treatment in end-stage disease;
- d) support for his family.

11.3 INTEGRATED SYSTEM OF HIV/AIDS AND TB CARE

An integrated system of HIV/AIDS and TB care uses available health systems to provide continuity of care for TB/HIV patients. The chart below shows an integrated system of HIV/AIDS and TB care.





11 3 1 Referral to local HIV/AIDS care services

One of the important features of a successful NTP is integration of TB control activities with the general health services (see Chapter 2). This means that at the district and primary health care levels, the general health service staff manage TB patients according to NTP guidelines, supported by NTP staff.

General health service and NTP staff need to know what local HIV/AIDS services are available for HIV-positive patients. Providers of local HIV/AIDS services include Ministry of Health, non-governmental organisations (NGOs) and community organisations. Often it is possible to refer patients directly to HIV/AIDS services.

Some TB/HIV patients choose not to accept referral to HIV/AIDS services. It is important to respect patients' wishes and confidentiality. In many districts there is a district coordinator for HIV/AIDS. District NTP staff liaison with the district coordinator for HIV/AIDS promotes the easy referral of TB-HIV patients to HIV/AIDS services.



In many towns and cities there are now HIV counselling and voluntary testing centres. Some of the people attending these centres may have TB. A study in Kampala, Uganda showed that 6% of people attending the HIV counselling and voluntary testing centre had undiagnosed TB. NTP collaboration with these centres is important. Staff in the centres should ask clients about chronic cough and refer TB suspects to the NTP for sputum microscopy.

11 3 3 Care in the community

General health services staff can refer patients directly to HIV/AIDS care services. Community care means providing the patient with access to care as close to home as possible. Some HIV/AIDS care services provide home care for AIDS patients. The home care provider may be a health care worker or community volunteer. See the WHO "AIDS Home Care Handbook" for more information.

Home care alone is not enough for a TB/HIV patient on a home care scheme. The TB patient needs to continue to receive his anti-TB treatment under direct observation by a trained and supervised home care provider. The HIV/AIDS home care scheme and the NTP can collaborate to train and supervise the HIV/AIDS home care provider to provide directly observed therapy. Also, the HIV/AIDS home care provider can recognise problems with anti-TB treatment and refer as necessary to the NTP.

11 3 4 Care at Primary Health Care Level

A good NTP is integrated with general health services (see Chapter 2). So primary health care staff are in a good position to identify and treat common HIV-related problems in patients during or after anti-TB treatment. Good communication between general health service staff and HIV/AIDS care workers is important for continuity of care of TB/HIV patients.

11 3 5 Private sector

The private sector includes private medical practitioners and traditional healers. Many patients choose to go to either or both.

Private medical practitioners

Ideally there should be close collaboration between private practitioners and the NTP. This results in improved management of TB patients according to NTP.



guidelines. However, a private practitioner serves the community and guarantees his TB patients good care by following NTP guidelines. A private practitioner can register the patient with the NTP and share continued management. A private practitioner does not have to give up his patient entirely to the NTP if he does not want to. Some TB/HIV patients prefer to go to a private practitioner for perceived reasons of confidentiality. In a country where the NTP is very good, many patients will prefer the NTP to a private practitioner.

Traditional practitioners

TB is a difficult disease for traditional practitioners. Many don't understand it, don't know how to cure it, and don't have the drugs. General health services can collaborate with traditional practitioners. For example, traditional practitioners can recognise who is a TB suspect and refer to the general health services. Traditional healers often have an important role in providing support to people with HIV-related diseases.

11.3.6 Care at District Level

Primary health care staff can manage many HIV-related problems in the health centres and dispensaries. Sometimes TB/HIV patients develop problems requiring investigations and treatment unavailable at primary health care level. Then they need referral to the District Hospital, either to the out-patient department or for admission. After appropriate district hospital management, often the district level staff can refer the patient back to the primary health care or community level. Good channels of communication promote continuity of care.

11.3.7 Tertiary referral care

District level staff sometimes deal with difficult problems of diagnosis or treatment. The patient may benefit from transfer to a tertiary referral hospital. It is usually wise to obtain advice on the telephone before transferring the patient. This is to ensure that the specialist agrees that the patient is likely to benefit from the referral.

SUGGESTIONS FOR FURTHER READING

- WHO Global Programme on AIDS. AIDS Home Care Handbook. Geneva, 1993
- WHO Global Programme on AIDS. Provision of HIV/AIDS care in resource-constrained settings. Report of a meeting. Geneva, 1994.

CHAPTER 12 PREVENTION OF TB IN HIV-INFECTED INDIVIDUALS

12.1 INTRODUCTION

From the public health point of view, the best way to prevent TB is to provide effective treatment to the infectious TB cases. This interrupts the chain of transmission. Good treatment programmes are the best prevention programmes. HIV-infected individuals are particularly susceptible to infection with *M. tuberculosis* and the development of TB. What are the ways of protecting HIV-infected individuals from exposure to TB in health care settings? What is the role of BCG? Can we do anything about those HIV-infected individuals who are already infected with *M. tuberculosis* and have a high risk of developing active TB? This chapter addresses these questions.

12.2 PROTECTION OF HIV-POSITIVE PERSONS AGAINST EXPOSURE TO TB.

HIV-positive patients and staff in health units face daily exposure to TB. The risk of exposure is greatest in adult medical wards and TB wards where there are many PTB cases. Often the wards are crowded and badly ventilated. We do not yet know the size of this risk.

Prompt diagnosis and treatment of patients with sputum smear-positive PTB helps to reduce exposure to TB. Out-patient diagnosis and treatment of PTB patients avoids hospital admission. This is an advantage in decreasing exposure to TB in hospital wards. In some NTPs there is a move away from an in-patient intensive phase towards out-patient management.

Known HIV-positive health workers should not work with PTB patients. They should therefore not work in TB wards or adult medical wards.

12.2.1 Environmental control

Good ventilation helps reduce TB transmission indoors. Sunlight is a source of ultraviolet light which can kill TB bacilli. So ideally, wards should have large windows.

In wards, out-patient clinics, sputum collection rooms, and microbiology laboratories, keep the doors closed and the windows open.

12 2 2 Face-masks

A face-mask decreases the risk that the person wearing the mask can infect other people. So a TB suspect or a TB patient, if possible, should wear a mask if moving from one part of a hospital to another.

Often a health worker wears a mask to protect himself against TB, e.g. when working on the TB ward. In fact, a mask is generally not very good at protecting the person wearing the mask from inhaling other people's infectious droplets. The exception is when the health worker is supervising a cough-inducing procedure, e.g. bronchoscopy, or sputum induction using nebulised hypertonic saline.

12 2 3 Patient education

Health workers should teach TB suspects and TB patients simple measures how to decrease the risk of transmitting TB. These include covering the mouth with the hand when coughing, and using sputum pots with lids. When examining TB patients or suspects, ask the patient to turn his head. This is to avoid him coughing directly at the health worker.

12 2 4 PTB suspects

In the majority of cases, PTB suspects attend as out-patients for the diagnosis of TB. In some cases it is necessary to admit PTB suspects to hospital. If possible admit them to a separate ward from other patients. There are often no facilities to separate PTB suspects from other patients. At least try to keep PTB suspects in a part of the ward away from other patients.

12 2 5 Patients with sputum smear-positive PTB

In many NTPs, sputum smear-positive PTB patients spend at least part, and often all, of the intensive phase of anti-TB treatment in hospital. Isolation of



12 3 THE ROLE OF BCG IN PREVENTING TB IN HIV-INFECTED INDIVIDUALS

12 3 1 Background

BCG (Bacille Calmette-Guerin) is a live attenuated vaccine derived originally from *M. bovis*. The route of injection is intra-dermal. The usual dose is 0.05 ml in neonates and infants under the age of 3 months, and 0.1 ml in older children. In high TB prevalence countries, WHO recommends a policy of routine BCG immunisation for all neonates shortly after birth.

The benefit of BCG is in protecting young children against disseminated and severe TB, e.g. TB meningitis and miliary TB. BCG has little or no effect in reducing the number of adult cases of PTB.

12 3 2 BCG protection against TB in HIV-infected children

It is not known if HIV infection reduces the protection of BCG against TB in children. There is some evidence that conversion to a positive tuberculin test after BCG is less frequent in HIV-infected children. The significance of this finding for protection against TB is not clear.

12 3 3 BCG safety in HIV-infected children

There have been a few case reports of local complications and disseminated BCG infection after BCG immunisation of HIV-infected children. However, prospective studies comparing BCG immunisation in HIV-infected and uninfected infants showed no difference in risk of complications. So, in the vast majority of cases, BCG immunisation is safe.

12 3 4 WHO recommended policy on BCG and HIV

WHO recommended policy depends on the TB prevalence in a country, as shown on the next page. In a high TB prevalence country, the possible benefits of BCG immunisation outweigh the possible disadvantages.



COUNTRY TB PREVALENCE WHO RECOMMENDED POLICY

high BCG for all children (according to standard programme) except children with symptoms of HIV disease/AIDS
low Do not give BCG immunisation to HIV-infected children

12 4 THE ROLE OF THE EXPANDED PROGRAMME ON IMMUNISATION (EPI)

BCG is not the only immunisation in the EPI which may help to protect a child against TB. Measles and whooping cough lower a child's resistance to TB. So whenever you treat a child for TB, check his immunisation record. If he has not received scheduled immunisations, encourage the mother to bring him for immunisations, once symptoms of TB have resolved. WHO has collaborated with UNICEF in establishing guidelines for immunisation. The recommendation is that individuals with known or suspected asymptomatic HIV infection should receive all EPI vaccines, according to national schedules.

12 5 PREVENTIVE TREATMENT

The aim of preventive treatment is to prevent progression of *M. tuberculosis* infection to disease. A 6 month course of preventive treatment with daily isoniazid (5 mg/kg) is effective. However, preventive treatment for all individuals infected with *M. tuberculosis* is not a recommended TB control strategy. It is not feasible to try to identify all individuals infected with *M. tuberculosis*. TB disease develops in only 10% of all individuals infected with *M. tuberculosis*. So it is not cost-effective to identify and treat all infected individuals in order to prevent disease in 10%.

However, it is possible to identify certain groups at high risk of progressing from *M. tuberculosis* infection to TB disease. It may be cost-effective to target preventive treatment at these high-risk groups.

12 5 1 Target groups for preventive treatment

Young children are at special risk, especially if they are HIV-infected. HIV infection, in children and in adults, is a potent cause of progression of *M. tuberculosis* infection to TB disease (see Chapter 1).

Infants of mothers with PTB

A breastfeeding infant has a high risk of infection from a mother with PTB,

and a high risk of developing TB. The infant should receive 6 months' isoniazid treatment, followed by BCG immunisation. An alternative policy is to give 3 months' isoniazid, then perform a tuberculin skin test. If the skin test is negative, stop the isoniazid and give BCG. If the skin test is positive, continue another 3 months' isoniazid, then stop isoniazid and give BCG.

Children under 5 years of age

It is important to screen child household contacts of adults with sputum smear-positive PTB (see Chapter 4). Screening identifies those children under 5 years of age without symptoms. Give these children 6 months' isoniazid preventive treatment. Children under 5 years of age with symptoms need investigation for TB. If investigations show TB, the child receives anti-TB treatment. If investigations do not show TB, the child should receive isoniazid preventive treatment.

HIV-infected individuals

Controlled clinical studies have shown that isoniazid preventive treatment reduces the risk of TB disease in HIV-positive individuals also infected with *M. tuberculosis*. The evidence of *M. tuberculosis* infection is a positive tuberculin skin test. In HIV-positive individuals, the extra benefit of a reduced risk of TB may also be a reduced rate of progression of HIV infection.

12 5 2 Role of isoniazid preventive treatment in HIV-positive individuals

The theoretical benefits of isoniazid preventive treatment are attractive. The table shows the potential disadvantages and necessary precautions.

POTENTIAL DISADVANTAGE	NECESSARY PRECAUTION
risk of drug toxicity respectively liver damage	do not give to people with chronic disease or who drink alcohol regularly
emergence of drug-resistance (if the patient has undetected TB disease and not just <i>M. tuberculosis</i> infection)	in all cases exclude TB disease by chest X-ray, in cases with cough of 3 weeks' duration or more by sputum microscopy
diversion of resources from NTP activities	funding must be from sources other than NTP (e.g. AIDS control programme, voluntary sector)

There are limitations in the feasibility of isoniazid preventive treatment on a wide scale in developing countries.

- Voluntary HIV testing is not widely available, so the number of suitable known HIV-positive persons is a small proportion of all HIV-positive persons.
- Resources are often inadequate to ensure satisfactory exclusion of TB disease, treatment compliance and patient monitoring for drug toxicity.
- When HIV-positive persons develop TB, we do not how many are due to reactivation of old infection and how many to new infection. Isoniazid preventive treatment will protect against new infection only during the 6 months of treatment. So the effectiveness of a course of isoniazid preventive treatment will be limited if TB is often due to new infections.
- Many HIV-positive persons infected with *M. tuberculosis* have a negative tuberculin skin test. So screening for *M. tuberculosis* by tuberculin skin testing will not identify all persons infected with *M. tuberculosis*.
- HIV-positive persons who feel well may be reluctant to accept TB screening and consideration of isoniazid preventive treatment.

Isoniazid preventive treatment programmes need evaluation. We need to know their cost, sustainability, potential impact, and effect on drug resistance. WHO does not at present recommend widespread isoniazid preventive treatment for HIV-positive persons in high TB prevalence countries. Isoniazid preventive treatment may have a role in selected groups (e.g. workers in a factory, health workers, soldiers) and in selected individuals.

SUGGESTIONS FOR FURTHER READING

- WHO. Expanded Programme on Immunisation. Childhood tuberculosis and BCG vaccination. BCG - gateway to EPI. Geneva: WHO, 1989.
- WHO. Global Programme for Vaccines and Immunisation. Immunisation Policy. Geneva, 1995.
- WHO/IUATLD. Tuberculosis preventive therapy in HIV-infected individuals. A joint statement of the WHO Tuberculosis Programme and the Global Programme on AIDS, and the International Union Against Tuberculosis and Lung Disease (IUATLD). Weekly Epidemiological Record 1993; 68: 361-364.
- O'Brien RJ, Perriens JH. Preventive therapy for tuberculosis in HIV infection: the promise and the reality. AIDS 1995; 9: 665-673.



Abscess	42, 44
lung	47
tuberculous lymphadenopathy	19, 39
Acid-fast bacilli	22, 58, 82
Adrenal gland tuberculosis	23, 26
AIDS	27
WHO clinical case definition	105
Anal/genital warts	69, 96, 114, 115, 116
Anaemia	107
Angular cheilitis	83, 84
Anti-TB drugs (see also essential TB drugs)	84
modes of action	107
Apthous ulcers	54
Ascites, tuberculous	43
Aspergilloma	42
Asthma	42, 44, 45, 67
Bacterial pneumonia	105
Bacterial vaginosis	125
BCG	125
HIV infection	126
infants of mothers with TB	125
WHO policy	47
Biopsy	48
diagnostic approach to extrapulmonary TB	55
lymph node	51
peritoneal TB	20, 62
pleural	22, 82
Blood spread of tubercle bacilli	38, 42, 46, 52
Bone TB	42, 44
Breathlessness	42, 43
Bronchial carcinoma	27, 75, 105, 106, 107
Bronchiectasis	89
Candidiasis	48
Capreomycin	79
Caseation	34, 37
Case definitions of tuberculosis	22, 38, 43, 44, 46
Case-finding	
Cavitation	



Cerebrospinal fluid	56, 111, 112
Cervicitis	104
Chancroid	104, 105
Chest pain	38, 46, 50, 52
Chest X-ray	31, 37, 42
Children	
approach to diagnosis	62
BCG	125
clinical recognition of HIV infection	75
contacts of infectious adults	67
counselling	76
differential diagnosis of pulmonary TB	67
Expanded Programme on Immunisation	126
HIV-related TB	31, 66
HIV testing	76
impact of HIV infection on TB diagnosis	66
preventive treatment	67, 126
score system for TB diagnosis	63
side effects of anti-TB drugs	96
"treatment trial"	65
tuberculin testing	65
Chlamydia	104
Chronic behaviour change	111
Chronic obstructive airways disease	42, 109
<i>Clostridium difficile</i>	108, 109
Code for TB treatment regimens	86
Cohort analysis	93
Congestive cardiac failure	42, 53
Conjunctivitis, phlyctenular	21
Connective tissue disease	44
Continuation phase of treatment	86, 87
Cough	19, 27, 37, 52, 62, 75, 109
Cryptococcal meningitis	26, 56, 112, 113
<i>Cryptosporidium</i>	108, 109
Culture, sputum	62
Cure, definition	92
Cycloserine	89
Cytomegalovirus	67, 108, 114, 117
Dacryitis, tuberculous	21
Default, definition	92

Desensitisation	10
Diarrhoea	26, 27, 59, 75, 10
Difficulty walking	11
Disseminated infection	11
Dysphagia	107, 10
Directly Observed Therapy (DOT)	35, 85, 12
District level care	12
Dormant TB bacilli	21, 8
Drug resistance	20, 33, 85, 8
Drug side effects	95, 9
Education of patients to prevent TB transmission	12
Environmental control measures to prevent TB transmission	123, 12
Erythema nodosum	2
Essential anti-TB drugs	84
Ethambutol	84, 96, 98, 114
Ethionamide	89
Extrapulmonary TB	22, 30, 46, 81, 82
Failure of treatment	87, 92
Face masks	124
Fever	27, 38, 64, 75, 97, 115
Fluorochrome stain	39, 40
Flow charts	
identification and management of child contacts	68
investigation of lymphadenopathy	48
management of HIV-positive TB patients who fail to respond or deteriorate while on anti-TB treatment	110
management approach for persistent headache	112
Gastric suction	62
Gastrointestinal tuberculosis	22, 58, 59, 64
Genital tract TB	22, 58
Genital ulcers	69, 104
Gibbus	58
Gingivitis	107
Gonorrhoea	104
Hairy leukoplakia	107
<i>Haemophilus influenzae</i>	110
Haemoptysis	38, 42, 43, 46
Hepatic TB	58, 59
Hepatitis	24, 96, 97, 98, 101
Herpes simplex	27, 75, 105

Herpes zoster

HIV

background information	23
epidemiology	23
HIV-related TB, basic facts	29
immunopathogenesis	25
natural history	25, 26
prevention of transmission in health units	24
58, 117	
Hypoadrenalism	21, 90, 101
Hypersensitivity reactions	
Immunisation (see also BCG and Expanded Programme on Immunisation)	125
Impeligo	106
Inguinal bubo	104
85, 87	
Initial phase of treatment	119, 120
Integrated HIV/AIDS and TB care	
68, 84, 95, 96, 98, 100, 114, 126, 127	
Isoniazid	108, 109
Isospora belli	89
Kanamycin	26, 27, 47, 52, 106, 116
Kaposi's sarcoma	62
Laryngeal swabs	
Lymph nodes	48
approach to investigation of lymphadenopathy	48, 49
biopsy	48
features of lymph nodes which indicate further investigation	49
histological appearance	26, 47
persistent generalised lymphadenopathy	22, 31, 47, 64
tuberculous lymphadenopathy	104, 105
Lymphogranuloma venereum	44, 47, 57, 67, 116
Lymphoma	62, 66
Malnutrition, children	26, 27, 56, 112, 113
Meningitis, cryptococcal	31, 55, 113
Meningitis, tuberculous	57
differential diagnosis	112
subacute/chronic meningitis	108, 109
Microsporidia	49, 87
Miliary TB	106
Molluscum contagiosum	89
Multi-drug resistant TB	19
Mycobacterium africanum	115, 116
Mycobacterium avium complex	

Mycobacterium tuberculosis	33, 34, 35, 36, 121
National Tuberculosis Programme	111, 112, 114
Neurosphilis	46, 110
Nocardia	44
Occupational lung disease	106
Papular folliculitis	20
Pathogenesis of TB	21, 22, 82, 90, 91
Pericarditis	52
Pericardial effusion	22, 31, 43, 50, 81, 82, 90
Pleural effusion, tuberculous	45, 46, 67
Pneumocystis carinii pneumonia	43, 51
Pneumothorax	21, 22, 62
Post-primary TB	90, 91, 99, 107, 108
Prednisolone (see also steroid treatment)	76, 89, 104
Pregnancy	123
Prevention of tuberculosis	125
BCG	123
environmental control measures	20, 21
Primary complex	121
Private medical practitioners	19, 20, 22, 30, 47, 62, 87, 91
Pulmonary TB	
adults	42
chest X-rays in diagnosis	37, 38
clinical features	37
diagnostic approach	38
diagnostic sputum smear microscopy	41, 42
differential diagnosis	44
differential diagnosis of chest X-ray findings	44
distinguishing other HIV-related pulmonary diseases	45, 46
patterns of disease	43
children	67
differential diagnosis in HIV-infected children	106
Psoriasis	112
Pyogenic brain abscess	106
Pyomyositis	84, 85, 88, 90, 96, 98, 100, 101
Pyrazinamide	95, 98, 114, 115
Pyridoxine	108
Rehydration	81, 82, 85, 87, 94
Relapse	



Renal disease	90, 117
Renal and urinary tract TB	22, 58, 90
Retreatment	86, 87
Rifampicin	84, 85, 88, 89, 90, 94, 96, 97, 98, 100, 117
Road to health card	63
Sarcoidosis	44, 116
Scabies	99, 106
Second-line drugs	89
Sexually transmitted diseases	23, 103
<i>Salmonella</i>	69, 108, 109, 115
Schistosomiasis	114
<i>Shigella</i>	108, 109
Short-course chemotherapy	34, 35, 83, 87
Skin TB	22
Source of TB infection	19, 34, 63
Spastic paraparesis	113
Spinal block, in tuberculous meningitis	90
Spinal cord disease	113, 114
Spinal TB	22, 58, 59, 113
Sputum smear microscopy	34, 37, 38
children	62
<i>Staphylococcus aureus</i>	110, 115
Steroid treatment, adjuvant	90, 91
<i>Streptococcus pneumoniae</i>	45, 110, 115
Streptomycin	84, 85, 88, 89, 90, 96, 98, 100, 101
Syphilis	
primary	104
meningitis	57, 111, 112, 114
Target groups for preventive treatment	126
Targets for TB control	33, 34
Thiacetazone	72, 84, 88, 90, 94, 96, 98, 99
Thrombocytopenia	69, 96, 97, 117
Tinea	106
Toxoplasmosis	112
Traditional practitioners	122
Transfer out, definition	92
Treatment of TB (see also anti-TB drugs)	34, 83, 119
default, definition	92
failure, definition	92
modes of action of anti-TB drugs	84, 85

monitoring of patients during treatment	91, 92, 93
National Tuberculosis Programmes	33, 34, 35, 36, 121
recommended treatment regimens	87
recording treatment outcome	92
recurrence	30, 94
response to treatment	93, 94
special situations	89, 90
standardised treatment categories	82
steroid treatment	90, 91, 99
treatment categories of TB	82
treatment regimens of anti-TB drugs	87
<i>Trichomonas vaginalis</i>	104, 105
Tubercle bacilli	19, 20, 38, 61
Tuberculin skin test	20, 37, 61, 63, 65, 66, 68, 127, 128
Tuberculosis (see also individual headings)	19
basic facts	19
control	33
diagnosis in adults	37
diagnosis in children	61
HIV-related, basic facts	29
pathogenesis	20, 62
prevention in HIV-infected individuals	123
TB suspect	34, 37, 38, 122, 124
treatment	34, 83, 87, 119
Urethral discharge	104
Vaginal discharge	104
Vaginitis	104
Voluntary HIV testing centres	121
Walking difficulty	113
Weight loss	26, 27, 37, 63, 75, 108, 115
Ziehl-Neelsen stain	39

7

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



Faithful but fearful: reducing HIV transmission in stable relationships

Isabelle de Zoysa^{*†}, Mich  el D. Sweat^{*†} and Julie A. Denison[†]

AIDS 1996, 10 (suppl A):S197-S203

Keywords: HIV prevention, stable relationships, heterosexual transmission, women, gender, communication

Introduction

Most HIV prevention efforts have focused on discouraging behaviors associated with a high risk of infection, such as having unprotected sex with numerous sexual partners. In addition, the majority of HIV control programmes have targeted 'core groups', that is, segments of the population with a high rate of sexual partner change who are considered to be high-frequency transmitters of HIV and other sexually transmitted diseases (STD) [1]. These approaches have helped to focus limited resources on behaviors that carry the highest risk of HIV infection, and on population groups that are critical for propagating and sustaining the epidemic. However, they have tended to convey the message that HIV infection can be avoided by keeping to a single partner and shunning members of identified core groups (such as sex workers). There is increasing concern that this does not serve the needs of the large number of persons who have only one stable partner but who are exposed to HIV infection because their partner was infected before the relationship began, or became infected following other sexual contacts or intravenous drug use [2-4].

In this article, we make the case for intensifying efforts to reduce HIV transmission in stable relationships. We argue that a significant and probably growing proportion of all HIV infections is being transmitted through sex with a stable partner, and describe the limitations of existing approaches to HIV prevention in addressing this problem. Finally, we discuss how to go beyond simple admonitions about monogamy or prescriptions about universal condom use to develop realistic solutions for reducing HIV transmission in stable relationships.

The risk of HIV transmission in stable relationships

How risky is sex with a stable partner?

Sexual and other risk behaviors are highly heterogeneous [5,6]. The risk of HIV transmission in stable relationships will therefore vary in different settings. Risk factor studies provide useful information on the behaviors that are associated with HIV infection in a particular setting. In general, such studies show that the relative risk of HIV infection increases rapidly with the number of sexual partners [7-12].

These results could indicate that persons who have remained with a single partner in recent years are at low risk of HIV infection. A closer look at the data from a risk factor study conducted in Rwanda shows how misleading this conclusion may be. In this study, Chao *et al.* [13] documented an overall HIV seroprevalence of 9.3% among a sample of 5690 pregnant women from a rural area around Butare. Seroprevalence was related to the number of sexual partners over the preceding 5 years. Seroprevalence was 56.4% among women who reported three or more sexual partners other than their current stable partner during that time. However, seroprevalence was still high, at 6.7%, among the women who reported only one sexual partner over the preceding 5 years. Furthermore, since women with only one recent partner formed the majority (83%) of the study population, the actual number of HIV infections they presented was higher than those found among women with three or more other partners (319 versus 53).

These findings are in line with other observations from similar settings [7,10] and indicate that a high rate of partner change is associated with an increased risk of

From the *Department of International Health, Johns Hopkins University, Baltimore, Maryland and the †AIDS Control and Prevention Project, Family Health International, Arlington, Virginia, USA.

Sponsorship: Supported by the AIDS Control and Prevention (AIDSCAP) Project of Family Health International under contract to the United States Agency for International Development.

Requests for reprints to: Julie A. Denison, AIDSCAP, Suite 700, 2101 Wilson Boulevard, Arlington, VA 22201, USA.

HIV. However, the risk of HIV infection remains unacceptably high among women who have no other risk factor than unprotected sex with a stable partner (even accounting for some underreporting of sexual partners). Because such persons form a sizable proportion of the population of sexually active adults, the attributable risk of this 'low-risk' behavior, that is, the proportion of all cases that can be attributed to the behavior at the population level, may be considerable.

These findings are not confined to sub-Saharan Africa. In the United States, heterosexual transmission of HIV may follow a similar pattern: most sexually active persons have only one stable partner, but a large number are indirectly exposed to HIV through their partner's sexual or drug-use behavior [14,15]. It may be that, in the United States, the number of sexual partners is not the dominant factor in heterosexual HIV transmission, at least for women [16].

The magnitude of HIV transmission in stable relationships is clearly context-specific. We predict, however, that it will occur to a significant degree under a wide variety of epidemiological scenarios. In settings where HIV transmission is highly focused among core groups — for example, a small number of female sex workers who have sex with a large number of men — infection is likely to be amplified and spread rapidly among the sex workers, with subsequent slower spread to male clients and, eventually, the stable partners of these men [17]. In the absence of vigorous and purposive action, extensive spread to these stable partners will be inevitable in countries such as Thailand [18], where most men who visit sex workers also have wives or other stable partners [19,20].

HIV transmission in stable relationships is also likely to be a problem where sexual networking extends throughout the population [21]. Mixing between groups with different levels of sexual activity may generate a slower but more widely disseminated spread of HIV infection, leading to a large epidemic in the so-called 'general population' [17]. In high HIV seroprevalence areas, a substantial proportion (14–19%) of couples are serodiscordant, exposing both men and women to the risk of acquiring HIV from their stable partner [22,23]. In low seroprevalence areas, repeat exposure to a single infected partner may be more important than a high rate of partner change, because the likelihood of selecting an infected partner in the first place is lower [24]. This is not to suggest that the number of partners is irrelevant; it is obvious that increasing the number of partners increases the risk of selecting an infected partner. The point is that limiting oneself to a single sexual partner is rarely entirely safe, and in some settings may be very risky.

Women at risk

An important observation is that the odds of HIV transmission in stable relationships are pitted against women. Women are biologically more vulnerable to HIV infec-

tion [6,25]. Women are also more likely to be exposed to sexual contact with a stable partner who is infected, for several reasons. First, in most areas, the prevalence of HIV infection is higher among men, increasing women's risk of selecting an HIV-infected partner [26]. Second, women enter their first union at a younger age, giving men more opportunity for sexual contacts before they enter a stable relationship [27,28]. Third, men tend to have a greater number of unions over their lifetime [28], and polygyny is more common than polyandry. Fourth, men have more sexual partners outside regular partnerships than women [5]. Women are therefore more likely than men to be infected by a stable partner. However, data to substantiate this point are scarce. Surveys that have identified HIV serodiscordant couples indicate that the male partner is the seropositive member in the majority of cases [24,29,30], although in some settings it is the other way around [22]. However, such cross-sectional surveys cannot determine whether these men and women were infected by earlier, long-term sexual partners, or by casual or commercial sex partners.

Barriers to the prevention of HIV transmission in stable relationships

Our concern is that, in some settings, sex with a stable partner carries a significant risk of HIV infection and represents a common route of transmission at the population level. Unfortunately, there is evidence that it can be difficult to apply recommended approaches to HIV prevention among persons in stable relationships. First, there is a widespread belief that sex with a stable partner carries few risks. Second, communication between stable partners about protective behaviors is compromised by prevailing norms about partner and gender relations. Third, condom use and other risk-reducing behaviors are problematic in long-term unions, not least because they preclude many of the expected benefits of such unions, such as procreation.

Assumptions of safety

Behavioral theory suggests that perceived risk of HIV infection is a powerful predictor of risk-reducing behavior [31–36]. Unfortunately, many seem unable or unwilling to recognize that they may be exposed to HIV infection in their stable relationship, even when they are aware of their partner's past or current risk behavior.

The dominant discourse in most settings implies that 'normal' sex with a stable partner is safe; it is sex 'outside' with occasional and therefore 'promiscuous' partners that is risky [37,38]. Many prevention messages, such as 'stick to your partner', 'love faithfully', or 'love carefully' reinforce the notion that HIV infection only strikes 'others' who deviate from the norm of loving, faithful and trusting relationships. Thus, monogamy is somehow constructed as a protection against HIV [4]; many believe

that they are not at risk of infection because they have only one sexual partner, even though they cannot vouch for their partner's behavior [39-41]. Furthermore, marriage and other stable relationships are frequently built on premises of trust, which require partners to accept that they are safe or else admit that the relationship has failed [42-44]. Acknowledging a partner's risk behavior may be too painful or threatening, as it raises other problems perceived to be more immediate and menacing than the risk of HIV [45]. 'Assumptions of safety' may overcome suspicions of danger [42].

Communication failures

Poor communications between men and women about sexual and reproductive health matters severely constrain the adoption of risk-reducing behaviors [46]. In the context of long-term relationships, opportunities for such communication may be even more remote, since partners believe that they 'know' each other and sexual activity is routine. It may be difficult for one of the partners to raise concerns about HIV transmission and attempt to change long-standing behavior patterns. This breaches norms of trust, silence and discretion [42-44], and may be interpreted as an accusation or a confession of infidelity.

Negotiations about safe sex within a particular relationship are also constrained by prevailing gender relations, which tend to discourage mutually respectful and equitable decision-making [46,47]. Whereas family systems and sexual roles vary tremendously across cultures [48], gender imbalances are widespread and entrenched. Women are frequently charged with the responsibility of initiating HIV preventive behaviors in stable relationships. They are often, for example, expected to challenge their partner about their risk behaviors, and to insist on condom use or refuse sex [39,49]. Some women do manage to effect behavior change, using persuasive, subversive, or, if necessary, confrontational techniques [39,50-52]. Unfortunately, most women are still at a stark disadvantage in relation to men in asserting their sexual and reproductive rights.

Challenging men's control over sexuality may be even harder in the context of marriage, as the majority of women, at least in the developing world, are socially and economically dependent on their spouses [53]. Legal and customary practices regarding child custody, property ownership and inheritance deny women assets that would enable them to negotiate effectively [46,48]. The irony is that where women's sexuality is very restricted, both their risk of contracting HIV from their partners [5] and their need to negotiate safer sex is greater, yet their bargaining power is weaker [46,54]. In these circumstances, their choices may be limited to 'social death or biological death' [55].

Meanings of safe sex

Mutual monogamy, partner reduction, condom use, and abstinence are among the safer sex options that are promoted by most HIV prevention programmes. What is the potential for their adoption within stable relationships?

Mutual monogamy is the only option that is specific to persons in stable relationships, and there is no doubt that it will be protective for many couples. However, mutual monogamy presumes that both partners have agreed to remain faithful, and will keep to the agreement. Furthermore, mutual monogamy is only useful if both partners are uninfected at the start of the relationship.

Many individuals, especially women, do not believe that their partners are faithful [50,56]. Their fears in many instances are well grounded. In 14 Global Programme on AIDS (World Health Organization)-supported sexual behavior surveys conducted in Africa, Asia and Latin America, the prevalence of sex outside stable relationships in the last 12 months ranged among men from 2 to 51% (median, 28%) and among women from 1 to 19% (median, 8%) [5]. The gender imbalance in these data reflect a pervasive double standard in which pre- and extramarital sex are condoned for men but condemned for women [48]. Women are more likely to remain 'faithful but fearful' [57].

Reducing the number of sexual partners is also not very helpful in decreasing the risk of HIV transmission in a stable relationship unless both partners change their behavior, as either partner may expose the other to HIV just as readily as a casual partner. Unfortunately, messages about partner reduction usually imply that individuals have a choice about their sexual relations. The reality is that social, structural and environmental factors play a major role in shaping sexual networking patterns and in influencing risk of HIV infection [58]. Migration and industrialization, for example, can lead to the separation or disruption of families on a massive scale, driving both men and women to seek partners other than their spouses for compelling emotional and practical reasons [48,55,59-61]. Poverty and economic stress take a particular toll on women who have fewer economic resources and opportunities. Many women have to take on additional sexual partners in exchange for the money, goods or favors required to ensure their survival and that of their children [4,48,55,62-64].

Condom use is the mainstay of efforts to reduce sexual transmission of HIV, but condom use is rare in stable relationships, except possibly in a few settings where condoms are actively promoted as contraceptives. There is little evidence that major changes are occurring yet in the face of AIDS. Numerous studies indicate that sex with a stable partner is less likely to be protected than sex with a casual partner [19,65,66]. Even persons who are convinced that condoms are effective and use them in casual relationships may not use them with their stable

partners, suggesting that there are other constraints at work. There are, for example, many reports of sex workers who insist on condom use with their clients, but do not use condoms with their husbands or lovers [67,68]. The fact is that condoms have been tainted by moral discourse [63,64]; they are deemed suitable for use with sex workers and occasional lovers [19,69], but not within a stable and caring relationship [38,70,71]. They are for 'women of the street, not the home' [3,72]. Numerous studies among HIV serodiscordant couples have shown that unprotected sexual relations may continue even when both partners know that one of them is seropositive and they have been counseled about the risk of transmission [23,29,73,74].

The potential for other safe sex practices is similarly constrained within stable relationships. Abstinence is an unlikely option, particularly for women in settings where sexual services are considered a conjugal right and a man's prerogative [53]. Even occasional refusal of sex may lead to problems [51,75], and, if prolonged, may be grounds for desertion or divorce [63]. Finally, a compelling problem with abstinence, non-penetrative sex or the use of barrier methods for protection against HIV infection is the effect on fertility. At the present time, couples who wish to have children have no way to eliminate possible transmission. Yet sexual relations and procreation are intimately linked in many cultures, and the ability to have children may be central to the self-worth of both men and women and the continuation of the union [69]. The prospect of childlessness may easily outweigh the risk of acquiring or transmitting HIV [52,64]. This may partly explain why counseling has a negligible effect on contraceptive use and pregnancy rates among seropositive women [76-80].

The way forward

The high cost of protective behaviors for persons in stable relationships suggests that blanket solutions, such as universal condom use, will not be appropriate or acceptable in most settings. Intervention approaches need to be developed that address the specific concerns and issues faced by persons in long-term unions. The social environment that affects behavioral change also needs to be addressed. We believe that action is needed on various fronts.

Implementing purposeful interventions

There is an urgent need to develop, strengthen and expand interventions that provide relevant HIV prevention services to persons who are in stable relationships and who are generally not targeted by HIV control activities. In the first instance, more should be made of existing programs, such as family planning and maternal health services, which are well-established in most areas. Such services provide unique opportunities to deliver STD diagnosis and treatment services to women, who

are generally poor users of STD clinics [81]. In addition, family planning programs could make a major contribution to increasing condom use, by emphasizing the dual role of condoms in preventing infections and unwanted pregnancies [82]. Finally, family planning and antenatal staff are well-placed to counsel women about their reproductive health and help them identify preventive measures suitable for their situation. More resolute and rapid expansion of efforts to integrate STD/HIV prevention activities into family planning and maternal health services is required, supported by research to resolve operational problems and to document and evaluate program activities.

Another intervention that is widely advocated for HIV prevention [83,84] and that may be particularly helpful to persons who are in stable relationships [75,85] is HIV counseling and testing. The potential contribution of voluntary HIV counseling and testing services to prevention efforts is still under debate, and there are concerns about the feasibility and cost of expanding such services in developing countries [86]. However, there is evidence that HIV counseling and testing directed beyond individuals to couples can lead to significant behavior change, especially in high seroprevalence areas [87]. Encouraging results have been found among discordant couples [23,29]. More research is needed to assess the acceptability and impact of HIV counseling and testing services for couples in facilitating communications about safer sex and in reducing risk-related behaviors.

Finally, more experience is needed in community-based approaches that encourage and facilitate behavior change in areas where HIV transmission in stable relationships is a concern. One innovative project in rural northeast Thailand demonstrates how cultural forces that put women at risk of HIV can be eroded through community action. Project activities aimed at changing community norms about HIV/AIDS involve married, monogamous women in encouraging their husbands to use condoms in commercial sex encounters and in discussing ways to ensure that HIV is not transmitted between them, thus breaking the 'norm of discretion and silence' [44]. Further efforts are urgently needed to develop interventions that engage individuals, groups, and communities in finding their own solutions to reduce HIV transmission in stable relationships.

Addressing gender inequalities

Interventions that enable and empower women to take action for HIV prevention are urgently needed. Encouraging results have been seen in peer support or community-level projects that build upon women's capacity for informal organization and existing support networks [52,54,88,89]. These projects have primarily targeted women, many of whom are in stable relationships, and have shown that women can be mobilized around the issue of HIV prevention and provided with the skills and support to negotiate safer sex with their

partners. However, these efforts are hampered by the fact that recommended methods for reducing HIV transmission are under the control of men. The development and evaluation of female-controlled methods of protection, which ideally can be used without men's consent, such as vaginal microbicides, is of highest priority [90-92].

However, an exclusive focus on women will be insufficient. Men still dominate decision-making in the sexual domain, and remain gatekeepers to sexual and reproductive behavior change [64,93,94]. Inevitably, the cooperation of both partners is required to negotiate and sustain HIV protection in a couple. Therefore, more attention is needed to understand and reconcile the contrasting perspectives of men and women, and to increase male responsibility in sexual and reproductive issues, including HIV prevention [93]. Real attempts to involve men in this way in either research or intervention projects are very scarce.

Tackling structural and environmental constraints

To effect pervasive and long-lasting shifts in behavior, action is needed to change the political, legal, social, economic, and environmental context in which such behavior changes take place. There have been few attempts to intervene on the structural and environmental levels to stem the HIV epidemic, and when such interventions have been attempted, they have rarely been evaluated [58]. Even small-scale environmental interventions could make a difference, such as providing migrant workers with housing and services for their families at their worksites [58]. Eventually, structural-level interventions, such as changes in laws and policies related to marriage, divorce and child custody, will be required to change social norms about sexual behavior and to create a supportive environment for more equitable decision-making in families.

Conclusions

Many uncertainties remain about the future course of the multiple epidemics that make up the HIV pandemic. Nevertheless, it is evident that increasing numbers of persons will acquire HIV from their stable partners. In the early phases of an HIV epidemic, infection is usually concentrated among groups of persons with high rates of sexual partner change. These core groups are at the center of sexual networks, and infection can spread rapidly through these networks to other persons. It is often said that those at the periphery, such as monogamous men and women, are of less public health significance because they are at the end of the line of transmission [95]. Unfortunately, this preoccupation with transmission dynamics has obscured the fact that very large numbers of people may be affected in this way.

Few HIV control programs have made a serious effort to deal with this problem. In fact, many programs have had the perverse effect of conveying the message that sex with a stable partner is safe sex and of limiting the use of condoms to high-risk situations. We believe that HIV control programs should reflect a greater awareness of the dynamic nature of the epidemic and concern about the full range of population groups who are affected. They need, of course, to work to change risk-taking behavior and should give due attention to core groups. However, they should also take into account the fact that many other persons may be at risk of HIV, not because of their own behavior, but because of the behavior of their partners.

We do not advocate an indiscriminating approach along the lines of 'everyone is at risk', which can lead to denial and dilute control efforts. Rather, we feel a need for carefully crafted messages that avoid stigmatizing specific groups and provide the required information and support to enable people to conduct their own risk assessment and to make their own informed choices about HIV protection. There are many constraints to behavior change in stable relationships, and it will be important to engage individuals, couples and communities in developing their own solutions to reduce the risk of HIV transmission.

None of this, however, will serve much purpose unless we confront the gender imbalances and structural factors that fuel the epidemic. Both men and women can acquire HIV infection from their stable partners [22], but women are more vulnerable because of gender-based power relationships, their social and economic dependency on men, and the pressure on them to bear children. They should not be expected to shoulder the responsibility for reducing HIV transmission, but be empowered to protect themselves and their families. Similarly, we need to go beyond interventions that seek only to modify the behavior of individuals without altering the forces that promote risk taking and discourage risk reduction. The containment of the HIV pandemic will only be possible in the long run if there is a commitment to social change.

Finally, a research agenda that supports these efforts needs to be developed and undertaken. First, descriptive research is required to better understand sexual behavior. These studies should go beyond a simple count of sexual partners to investigate sexual networks and sexual roles and to explore communication and negotiation processes within different types of partnerships. Second, intervention-related research is urgently needed to develop and evaluate promising approaches to behavior change in stable relationships. Finally, biomedical research is required to develop improved technologies to reduce the risk of HIV transmission. Of greatest importance are female-controlled methods of protection, particularly methods that reduce the risk of infection without precluding procreation.

References

- Over M, Piot P: HIV infection and sexually transmitted diseases. In *Disease Control Priorities in Developing Countries*. Edited by Jamison DT, Mosley WH, Measham AR, Bobadilla JL. Oxford: Oxford University Press; 1993:455-527.
- Rodrigues LC, Evans B, Peter K: Heterosexual transmission of HIV (letter). *BMJ* 1992, 305:364.
- Gupta GR, Weiss E: Women's lives and sex: implications for AIDS prevention. *Cult Med Psychiatry* 1993, 17:399-412.
- Heise LL, Elias C: Transforming AIDS prevention to meet women's needs: a focus on developing countries. *Soc Sci Med* 1995, 40:931-943.
- Carael M, Cleland J, Ingham R: Extramarital sex: implications of survey results for STD/HIV transmission. *Health Transition Rev* 1994, 4 (suppl):153-172.
- Fontanet A, Piot P: State of our knowledge: the epidemiology of HIV/AIDS. *Health Transition Rev* 1994, 4 (suppl):11-23.
- Allen S, Lindan C, Serufilira A, et al.: Human immunodeficiency virus infection in urban Rwanda: demographic and behavioral correlates in a representative sample of childbearing women. *JAMA* 1991, 266:1657-1663.
- Barongo LR, Borgdorff MW, Mosha FF, et al.: The epidemiology of HIV-1 infection in urban areas, roadside settlements and rural villages in Mwanza Region, Tanzania. *AIDS* 1992, 6:1521-1528.
- Hunter DJ, Maggwa BN, Mati JKG, Tukei PM, Mbugua S: Sexual behavior, sexually transmitted diseases, male circumcision and risk of HIV infection among women in Nairobi, Kenya. *AIDS* 1994, 8:93-99.
- Kapiga SH, Shao JF, Lwihula GK, Hunter DJ: Risk factors for HIV infection among women in Dar-es-Salaam, Tanzania. *J Acquir Immune Defic Syndr* 1994, 7:301-309.
- Malamba SS, Wagner H-U, Maude G, et al.: Risk factors for HIV-1 infection in adults in a rural Ugandan community: a case-control study. *AIDS* 1994, 8:253-257.
- Nelson KE, Celentano DD, Suprasert S, et al.: Risk factors for HIV infection among young adult men in Northern Thailand. *JAMA* 1993, 270:955-960.
- Chao A, Bulterys M, Musanganire F, et al.: Risk factors associated with prevalent HIV-1 infection among pregnant women in Rwanda. *Int J Epidemiol* 1994, 23:1-10.
- Kost K, Forrest JD: American women's sexual behavior and exposure to risk of sexually transmitted diseases. *Fam Plann Perspect* 1992, 24:244-254.
- Prevots DR, Ancelle-Park RA, Neal JJ, Remis RS: The epidemiology of heterosexually acquired HIV infection and AIDS in Western industrialized countries. *AIDS* 1994, 8 (suppl 1):S109-S117.
- Carpenter CCJ, Mayer KH, Stein MD, Leibman BD, Fisher A, Fiore T: Human immunodeficiency virus infection in North American women: experience with 200 cases and a review of the literature. *Medicine* 1991, 70:307-325.
- Anderson RM, May RM, Baily MC, Garnett GP, Rowley JT: The spread of HIV-1 in Africa: sexual contact patterns and the predicted demographic pattern of AIDS. *Nature* 1991, 352:581-589.
- Weniger BG, Limpakarnjanarat K, Ungchusak K, et al.: The epidemiology of HIV infection and AIDS in Thailand. *AIDS* 1991, 5 (suppl 2):S71-S85.
- Havanon N, Bennett A, Knodel J: Sexual networking in provincial Thailand. *Stud Fam Plann* 1993, 24:1-17.
- Podhisita C, Morris M, Waver M: Bridge populations in the spread of HIV/AIDS in Thailand. *X International Conference on AIDS/STD World Congress*. Yokohama, August 1994 [abstract PCO120].
- Orubuloye IO, Caldwell JC, Caldwell P: Diffusion and focus in sexual networking: identifying partners and partners' partners. *Stud Fam Plann* 1992, 23:343-351.
- Serwadda D, Gray RH, Waver MJ, et al.: The social dynamics of HIV transmission as reflected through discordant couples in rural Uganda. *AIDS* 1995, 9:745-750.
- Allen S, Tice J, Van de Perre P, et al.: Effect of serotesting with counselling on condom use and seroconversion among HIV discordant couples in Africa. *BMJ* 1992, 304:1605-1609.
- Padian N: Heterosexual transmission: infectivity and risks. In *Heterosexual Transmission of AIDS*. Edited by Alexander NJ, Gabelrick HL, Spieler JM. New York: Wiley-Liss; 1990:25-34.
- Johnson AM: Condoms and HIV transmission. *N Engl J Med* 1994, 331:391-392.
- Ellerbrock TV, Bush TJ, Chamberland ME, Oxtoby MJ: Epidemiology of women with AIDS in the United States, 1981 through 1990: a comparison with heterosexual men with AIDS. *JAMA* 1991, 265:2971-2975.
- Carael M, Cleland J, Adekun L, et al.: Overview and selected findings of sexual behaviour surveys. *AIDS* 1991, 5 (suppl 1):S65-S74.
- Palloni A, Lee YJ: Some aspects of the social context of HIV and its effects on women, children and families. *Popul Bull United Nations* 1992, 33:64-87.
- Kamenga M, Ryder RW, Jingu M, et al.: Evidence of marked sexual behavior change associated with low HIV-1 seroconversion in 149 married couples with discordant HIV-1 serostatus: experience at an HIV counselling center in Zaire. *AIDS* 1991, 5:61-67.
- Roongpisuthipong A, Siriwasin W, Chaiyakul P, et al.: Husband HIV discordance among HIV-infected pregnant women, Bangkok, Thailand. *X International Conference on AIDS/STD World Congress*. Yokohama, August 1994 [abstract 103C].
- Catania JA, Kegeles SM, Coates TJ: Towards an understanding of risk behavior: an AIDS risk reduction model (ARRM). *Health Educ Q* 1990, 17:53-72.
- Ajen I, Fishbein M: *Understanding Attitudes and Predicting Behavior*. Englewood Cliffs, NJ: Prentice Hall; 1980.
- Becker MH, Janz NK: On the effectiveness and utility of health/hazard risk appraisal in clinical and nonclinical settings. *Health Serv Res* 1987, 22:537-551.
- Green LW, Kreuter MW, Deeds SC, Partridge KB: *Health Education Today and the PRECEDE Framework*. Palo Alto: Mayfield; 1979.
- Leventhal H, Meyer D, Nerenz D: The common sense representation of illness danger. In *Medical Psychology*. Edited by Rachman S. New York: Pergamon Press; 1980:7-30.
- Sweat MD: *The Social Construction of Risk: AIDS Knowledge and Risk Perception Among the US Population (PhD Dissertation)*. Atlanta, GA: Emory University; 1992.
- Patton C: 'With champagne and roses': women at risk from/in AIDS discourse. In *Women and AIDS: Psychological Perspectives*. Edited by Squire C. Newbury Park: Sage Publications; 1993:165-187.
- Waldby C, Kippax S, Crawford J: Cordon sanitaire: 'clean' and 'unclean' women in the AIDS discourse of young heterosexual men. In *AIDS: Facing the Second Decade*. Edited by Aggleton P, Davies P, Hart G. New York: Falmer Press; 1993:29-38.
- Carovano K, Middlestadt SE: Understanding women's prevention behavior. In *A World Against AIDS: Communication for Behavior Change*. Edited by Smith WA, Helquist MJ, Jimerson AB, Carovano K, Middlestadt SE. Washington, DC: Academy for Educational Development; 1993:107-127.
- Forrest KA, Austin DM, Valdes MI, Fuentes EG, Wilson SR: Exploring norms and beliefs related to AIDS prevention among California Hispanic men. *Fam Plann Perspect* 1993, 25:111-117.
- Maticka-Tyndale E, Kiewying M, Haswell-Elkins M, et al.: Knowledge, attitudes and beliefs about HIV/AIDS among women in Northeastern Thailand. *AIDS Educ Prev* 1994, 6:205-218.
- Willig C: Marital discourse and condom use. In *AIDS: Foundations for the Future*. Edited by Aggleton P, Davies P, Hart G. Bristol, PA: Taylor & Francis; 1994:110-122.
- Holland J, Ramazanoglu C, Scott S, Sharpe S, Thomson R: Risk, power and the possibility of pleasure: young women and safer sex. *AIDS Care* 1992, 4:273-283.
- Maticka-Tyndale E, Haswell-Elkins M, Kuyyakanond T, Kiewying M, Elkins D: A research-based HIV intervention in Northeast Thailand. *Health Transition Rev* 1994, 4 (suppl):349-367.
- Moore JS, Harrison JS, Doll LS: Interventions for sexually active, heterosexual women in the United States. In *Preventing AIDS: Theories and Methods of Behavioral Interventions*. Edited by DiClemente RJ, Peterson JL. New York: Plenum Press; 1994:243-265.
- Mane P, Gupta GR, Weiss E: Effective communication between partners: AIDS and risk reduction for women. *AIDS* 1994, 8 (suppl 1):S325-S331.
- Dixon-Mueller R: The sexuality connection in reproductive health. *Stud Fam Plann* 1993, 24:269-282.
- Larson A: Social context of human immunodeficiency virus transmission in Africa: historical and cultural bases of East and Central African sexual relations. *Rev Infect Dis* 1989, 2:716-731.
- O'Neil C, Rosenbaum J: Women protecting themselves: an intervention study to heighten monogamous women's perception of risk in light of partner behaviour. *IX International Conference on*

- AIDS/IV STD World Congress. Berlin, June 1993 [abstract WS-D18-4].
50. Lindan C, Allen S, Carael M, et al.: Knowledge, attitudes, and perceived risk of AIDS among urban Rwandan women: relationship to HIV infection and behavior change. *AIDS* 1991, 5:993-1002.
 51. Orubuloye IO, Caldwell JC, Caldwell P: African women's control over their sexuality in an era of AIDS: a study of the Yoruba of Nigeria. *Soc Sci Med* 1992, 37:859-872.
 52. Schoepf BG: AIDS action-research with women in Kinshasa, Zaire. *Soc Sci Med* 1993, 37:1401-1413.
 53. Awusabo-Asare K, Anarfi JK, Agyeman DK: Women's control over their sexuality and the spread of STDs and HIV/AIDS in Ghana. *Health Transition Rev* 1993, 3 (suppl):69-84.
 54. Norr KF, McElmurry BJ, Moeti M, Tlou SD: AIDS prevention for women: a community-based approach. *Nurs Outlook* 1992, 40:250-256.
 55. Bassett MT, Mhloyi M: Women and AIDS in Zimbabwe: the making of an epidemic. *Int J Health Serv* 1991, 21:143-156.
 56. McGrath JW, Rwabukwali CB, Schumann DA, et al.: Anthropology and AIDS: the cultural context of sexual risk behavior among urban Baganda women in Kampala, Uganda. *Soc Sci Med* 1993, 36:429-439.
 57. Rodrigues L, Moreno CG: HIV transmission to women in stable relationships [letter]. *N Engl J Med* 1991, 32:966.
 58. Sweat MD, Denison JA: Reducing HIV incidence in developing countries with structural and environmental interventions. *AIDS* 1995, 9 (suppl A):S251-S257.
 59. Hunt CW: Migrant labor and sexually transmitted disease: AIDS in Africa. *J Health Soc Behav* 1989, 30:353-373.
 60. Jochelson K, Mothibeli M, Leger JP: Human immunodeficiency virus and migrant labor in South Africa. *Int J Health Serv* 1991, 21:157-173.
 61. Pison G, Le Guenno B, Lagarde E, Enel C, Seck C: Seasonal migration: a risk factor for HIV infection in rural Senegal. *J Acquir Immune Defic Syndr* 1993, 6:196-200.
 62. Romero-Daza N: Multiple sexual partners, migrant labor, and the makings of an epidemic: knowledge and beliefs about AIDS among women in Highland Lesotho. *Hum Org* 1994, 53:192-205.
 63. Schoepf BG: Women, AIDS, and economic crisis in Central Africa. *Can J Afr Stud* 1988, 12:625-644.
 64. Ulin P: African women and AIDS: negotiating behavioral change. *Soc Sci Med* 1992, 34:63-73.
 65. Bertrand JT, Makani B, Hassig SE, et al.: AIDS-related knowledge, sexual behavior, and condom use among men and women in Kinshasa, Zaire. *Am J Public Health* 1991, 81:53-58.
 66. Choi K, Catania J, Dolcini MM: Extramarital sex and HIV risk behavior among US adults: results from the National AIDS Behavioral Survey. *Am J Public Health* 1994, 84:2003-2007.
 67. Avila MH, Zuniga PU, de Zalduondo BO: Diversity in commercial sex work systems: preliminary findings from Mexico City and their implications for AIDS interventions. In *AIDS and Women's Reproductive Health*. Edited by Chen LC, Sepulveda-Amor J, Segal SJ. New York: Plenum Press; 1991.
 68. Hooykaas C, van der Pligt J, van Doornum GJJ, van der Linden MMD, Coutinho RA: Heterosexuals at risk for HIV: differences between private and commercial partners in sexual behaviour and condom use. *AIDS* 1989, 3:525-532.
 69. Worth D: Sexual decision-making and AIDS: why condom promotion among vulnerable women is likely to fail. *Stud Fam Plann* 1989, 20:297-307.
 70. Del Riego A, Reingold A, Hearst N: Attitudes regarding high risk sexual behaviors and condom use among women in the Dominican Republic: study of the urban population of Santo Domingo. *X International Conference on AIDS/IV STD World Congress*. Yokohama, August 1994 [abstract PD0121].
 71. Sobo EJ: Inner-city women and AIDS: the psycho-social benefits of unsafe sex. *Cult Med Psychiatry* 1993, 17:455-485.
 72. Goldstein DM: AIDS and women in Brazil: the emerging problem. *Soc Sci Med* 1994, 39:919-929.
 73. Padian NS, O'Brien TR, Change Y, Glass S, Francis D: Prevention of heterosexual transmission of human immunodeficiency virus through couple counseling. *J Acquir Immune Defic Syndr* 1993, 6:1043-1048.
 74. De Vincenzi I: A longitudinal study of human immunodeficiency virus transmission by heterosexual partners. *N Engl J Med* 1994, 331:341-346.
 75. van der Straten A, King R, Grinstead O, Serufilira A, Allen S: Couple communication, sexual coercion and HIV risk reduction in Kigali, Rwanda. *AIDS* 1995, 9:935-944.
 76. Allen S, Serufilira A, Gruber V, et al.: Pregnancy and contraception use among urban Rwandan women after HIV testing and counseling. *Am J Public Health* 1993, 83:705-710.
 77. Heyward WL, Batter VL, Malulu M, et al.: Impact of HIV counseling and testing among child-bearing women in Kinshasa, Zaire. *AIDS* 1993, 7:1633-1637.
 78. Higgins DL, Galavotti C, O'Reilly KR, et al.: Evidence for the effects of HIV antibody counseling and testing on risk behaviors. *JAMA* 1991, 266:2419-2429.
 79. Ryder RW, Batter VL, Nsuami M, et al.: Fertility rates in 238 HIV-1-seropositive women in Zaire followed for 3 years post-partum. *AIDS* 1991, 5:1521-1527.
 80. Temmerman M, Moses S, Kiragu D, Fusallah S, Wamola IA, Piot P: Impact of single session post-partum counseling of HIV infected women on their subsequent reproductive behaviour. *AIDS Care* 1990, 2:247-252.
 81. Laga M: STD control for HIV prevention - it works! *Lancet* 1995, 346:518-519.
 82. Cates W: Sexually transmitted diseases and family planning: strange or natural bedfellows, revisited. *Sex Transm Dis* 1993, 20:174-178.
 83. Müller O, Phanuphak P: Voluntary HIV counseling and testing in developing countries [letter]. *Lancet* 1993, 342:1117.
 84. Phanuphak P, Müller O, Sarangbin S, Sittitai W: Knowledge, attitudes and behaviour among HIV-positive and HIV-negative clients of a confidential HIV counselling and testing centre in Thailand. *AIDS* 1994, 8:1315-1319.
 85. King R, Allen S, Serufilira A, Karita E, Van de Perre P: Voluntary confidential HIV testing for couples in Kigali, Rwanda [letter]. *AIDS* 1993, 7:1393-1394.
 86. De Zoysa I, Phillips KA, Kamenga MC, et al.: Role of HIV counseling and testing in changing risk behavior in developing countries. *AIDS* 1995, 9 (suppl A):S95-S101.
 87. Allen S, Serufilira A, Bogaerts J, et al.: Confidential HIV testing and condom promotion in Africa: impact on HIV and gonorrhea rates. *JAMA* 1992, 268:3338-3343.
 88. Kelly JA, Murphy DA, Washington CD, et al.: The effects of HIV/AIDS intervention groups for high-risk women in urban clinics. *Am J Public Health* 1994, 84:1918-1922.
 89. Patton C: Planning for women. In *Last Served: Gendering the HIV Epidemic*. Edited by Aggleton P. Bristol, PA: Taylor & Francis, 1994:120-157.
 90. Elias CJ, Heise L: *The Development of Microbicides: a New Method of HIV Prevention for Women*. Working Paper No. 6. New York: The Population Council; 1993.
 91. Rosenberg MJ, Holmes KK, World Health Organization Working Group on Virucides: Virucides in the prevention of HIV infection: research priorities. *Sex Transm Dis* 1993, 20:41-44.
 92. Stein ZA: HIV prevention: the need for methods women can use. *Am J Public Health* 1990, 80:460-462.
 93. Bongaarts J, Bruce J: The causes of unmet need for contraception and the social content of services. *Stud Fam Plann* 1995, 26:57-75.
 94. Ezech AC: The influence of spouses over each other's contraceptive attitudes in Ghana. *Stud Fam Plann* 1993, 24:163-174.
 95. Caldwell JC: Understanding the AIDS epidemic and reacting sensibly to it. *Soc Sci Med* 1995, 41:299-302.

8

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



Stress and burnout in HIV/AIDS carers

David Miller

AIDS 1996, 10 (suppl A):S213-S219

Keywords: HIV, AIDS, work stress, carers, burnout, fear, staff support

Introduction

Awareness of work stress and burnout in health work has, after initial work in the 1970s and early 1980s, been given renewed impetus by recent research in the field of HIV/AIDS care. Since 1991, reports from many, mainly developed, countries have identified more reliably the factors that are associated with chronic work stress and with work reward, and gradually more reports are suggesting means by which both organizations and their staff may counter such stresses and prevent them in future. Early work on burnout in the field of HIV/AIDS characterized levels of self-reported stress in HIV/AIDS workers [1,2] along with elements of clinical engagement that contributed to stress in AIDS care. These included identification with gay or lesbian clients and with possible HIV risk [1], the relative youth of patients and the nature of disease manifestations, as well as the absence of effective cures or interventions [3], resource shortages and absence of clinical variation [4,5]. Subsequent work has seen the increasing use of standardized instruments of measurement in HIV/AIDS burnout studies, and recent reports have focused on the relations of burnout subscales to occupational field, profession, volunteerism, personality and non-work arenas. Suggestions for burnout management have grown more practical as characterization data has improved across studies.

Characteristics of work stress in HIV/AIDS carers

Studies of work stress in HIV/AIDS care routinely appear to find high levels of morbidity [5-11]. For example, a London study comparing 100 oncology and 103 HIV/AIDS staff found that 41% overall scored as being vulnerable psychiatric screening instruments, and 70 and 61%, respectively, scored as having moderate-high emotional exhaustion and reduced sense of personal accomplishment [11].

An issue emerging from data in the past year is the degree to which the stresses of HIV/AIDS care are unique. A longitudinal study involving a total of 708 health staff from the fields of HIV/AIDS, oncology and geriatrics [7] examined responses to survey questionnaires incorporating the 'emotional exhaustion', 'depersonalization' and 'reduced personal accomplishment' subscales of the Maslach Burnout Inventory (MBI) [12], and questions relating to social support and coping, at three 11-month intervals. The three MBI subscales reflect the degree to which respondents are emotionally overextended and exhausted by work, unfeeling and impersonal in responding to patients, and feeling competent and successfully achieving in their work, respectively. Workers in the AIDS field showed significantly lower mean scores for emotional exhaustion and burnout than workers in oncology and geriatrics. Curiously, confrontation with death and dying occurred significantly more often in the fields of geriatrics and cancer care than in AIDS care, although this appeared to have a stronger impact on emotional exhaustion in AIDS workers than in staff from the other fields. Overall, AIDS staff reported significantly fewer problems interacting with clients than workers in the other fields. Where such problems occurred, they led to a significant increase in feelings of personal accomplishment in AIDS staff, whereas they had the opposite effect in geriatric and oncology staff. The authors concluded that AIDS care problems actually appear to promote a sense of professional identity, by confirming professional identities and esteem. Similarly, a London study comparing HIV with oncology staff [11] found that stresses reported by oncology staff were environmental and contextual, rather than the personal stress issues identified by HIV/AIDS staff. Such differences were attributed to there being a more binding ethos affecting perceptions of work stress in HIV/AIDS care. Reported stresses were thus internally focused, rather than the more external focus on stressful work conditions that the oncology staff reported.

Previous studies in the field of staff stress and burnout have examined differences in work stress susceptibility

From the Academic Department of Sexually Transmitted Diseases, University College London Medical School, Camden and Islington CHS NHS Trust, The Mortimer Market Centre, London, UK.

Requests for reprints to: David Miller, Academic Department of Sexually Transmitted Diseases, University College London Medical School, Camden and Islington CHS NHS Trust, The Mortimer Market Centre, Mortimer Market, London WC1E 6AU, UK.

associated with gender [13], experience [5,11], role content and ambiguity [14], workload [15], conflicts between individual aspirations and organizational ethos [16,17], and AIDS concern associated with stigma and fear of infection [18]. A more recent study has examined differences in work stress susceptibility associated with profession. The London-based Multicentre Occupational Morbidity Study (MOMS) study [11] found that physicians were more likely than nurses or paramedical staff to conclude that better service management and fewer patients would reduce work stress. Nurses, on the other hand, felt that stress would be reduced by having more staff and resources. Nurses were also significantly more likely to report stress associated with breaking bad news, and to have consulted a physician in the 6 months prior to interview. Paramedical staff felt that work stress would be reduced by having better service management, and felt personally obstructed by colleagues more often than nurses or physicians. Despite these differences, there were no differences between occupational groups, or groups associated with HIV/AIDS or oncology on psychometric indices of work-related stress or psychological vulnerability.

A Berlin study [7], however, did find that AIDS staff had less time pressure and fewer problems interacting with their patients. When examining results by occupational group, these researchers found that with HIV/AIDS care, psychosocial occupations had elevated emotional exhaustion and depersonalization compared to medical and nursing professions, although the reverse was found for oncology and geriatric care staff. Medical and nursing staff reported greater levels of social support in the workplace than psychosocial professions [7,19] — the social support buffer hypothesis [17] is gaining increasing support in HIV/AIDS research [20].

Increasingly, findings are confirming the importance of many other factors in HIV staff stress. For example, clinical and social stresses in HIV/AIDS work appear to have been compounded by the high profile, sensationalist and often contradictory media emphases that the pandemic has attracted, due in part to public stigma and fear associated with myths about homosexuality [21]. In addition, HIV/AIDS staff are required to cope with the elevated stress, fears of death and anxiety associated with identifying with patients from their own age and peer groups [1,3], and with the grieving of patients and of their loved-ones and families [22,23]. Intense relationships have been reported to develop between carers and individuals with HIV, and the organizations representing them [22]. Numbers of AIDS patients seen by nurses over a 6-month period are significantly predictive of MBI-measured emotional exhaustion, and both numbers of patients seen and increases in workload or responsibility have been shown as positively related to distress in nursing staff [15]. Furthermore, health-care workers in the HIV/AIDS field, particularly in the first few years of the epidemic, experienced often unavoid-

able role expansion as the novel pressures of their work have demanded unprecedented and sometimes acute advocacy, media participation, involvement in health policy formation and teaching of colleagues [24].

However, the notion of reward and intellectual stimulation [1] counterbalancing the negative aspects of work that manifest as burnout has been developed psychometrically and increasingly endorsed [8,19,25].

Fear in AIDS care

Continually pressing dimensions to HIV work stress are the fear of infection, social contamination, discomfort with the sexual dimensions of AIDS, the sense of professional inadequacy, and reward and challenge [26]. Relations of trained staff to persons known to have HIV or to those identified with them by social group and affiliation remain complex [27]. Training in HIV and infection control does not automatically confer rationality in the practice of health care [28] (a lesson learned also in the context of health education and behaviour change in those at risk for HIV). Nurses, physicians, medical students and professions allied to medicine have, in many studies, all revealed a discrepancy between what they have been taught and what they do in practice, and also between attitudes and training [18], although an interesting and recurrent finding in such studies is that experience and age appear to have protective effects being associated with significantly lower levels of psychometrically measured work stress and burnout [5,11,29]. There has been little empirical examination of the nature of interactions between health workers and individuals with HIV since the ground-breaking work in this field [2,27], although surveys of medical students in their third and fourth years illustrate that estimates of risk of seroconversion following needlesticks and even decisions about choice of medical speciality or worksite may often be based on active misperceptions that affect practice [30].

The significance of fear and stigma in HIV care for determination of ethical practice has been explicated in renewed debate, which can apply with equal importance to non-HIV/AIDS fields of health care, regarding the linkage of public health and human rights [31,32].

The growing recognition of stress in HIV/AIDS volunteers

An important and, until recently, neglected area of HIV health worker research has been the interplay between voluntary and statutory service personnel and the meaning that relationships of this sort may have for the development of stress and burnout. This area is important because in many countries it is volunteer helpers who provide the bulk of community care and support for those with HIV, and without their continued efforts the edifice of community care for HIV/AIDS would be in danger of collapse [33,34]. An Australian study [35] found that stressors for HIV/AIDS volunteers were emotional overload, client problems for which they felt inadequately prepared, and lack of support and training.

In addition, rewards associated with volunteer work were identified as personal effectiveness, emotional support, social support, and empathy/'self-knowing'.

A study of 1300 HIV/AIDS volunteers in Houston religious organizations [36] reported that low levels of volunteer burnout could be attributed to volunteers opting in to care for others, having a strong religious ethos of compassionate support, close support being given to volunteer team bereavements, and psychosocial support arising from regular team meetings. A subsequent questionnaire survey of 174 religious volunteers in Houston [37] found no statistically significant association between burnout and self-reported grief, although grief was independently associated with having less time and therefore experience as a volunteer, and with being unable to avoid the intense emotion that AIDS care can generate. These authors suggest that volunteer vulnerability to MBI-measured burnout may be reduced if they have more choice over where they volunteer, how much time they do it, and over staying in or leaving the field. The strongest predictors of grief in this sample were having less time as a volunteer, emotional overload, and feeling rewarded by emotional support.

Volunteer cohorts have been used to assess the role of recognition and reward [25], and social support [20] as burnout buffers. Lack of training and absence of a sense of personal effectiveness are independently associated with increased frequency of MBI-measured burnout. Support in the workplace thus appears to require greater focus on training opportunities for skills enhancement [25].

On scales measuring stress, social support, burnout and rewards, 265 HIV/AIDS volunteers in New York revealed that heightened social support leads to heightened rewards in volunteering, which in turn generated a lack of boundaries between volunteer work and other life roles [20]. Increased perception of personal efficacy decreased the desire to stop volunteering, especially where support came from fellow volunteers, and the more volunteers felt supported by staff, the more effective they felt. Volunteer retention had been predicted where there was a high need for personal support and personal control found in earlier studies of volunteer populations in London [38], although a further London study had found that poor volunteering outcomes were associated with wanting to feel needed and wanting to help others [39]. Maslanka [20] observed that support in the job may not be as important for staff stress reduction as designing stress prevention into training activities for volunteers and staff supervising them. Such training should include clarification of organizational expectations of individual achievement [16].

Social context and social support

The importance of social context in development and prevention of burnout had been predicted in much of the pre-AIDS work on burnout in health care [40-42].

This area of research is especially useful as it opens up empirically-based options for management. A study from Australia [19] involving self-report questionnaire responses of 54 nurses, 16 physicians and 14 social workers found that burnout score was defined as a function of social context and the nature of the job rather than who was doing the job. Those with higher scores of burnout had higher levels of stigma and external coping, whereas those with lower scores had higher levels of internal coping, social recognition and support in the workplace. The authors concluded that burnout may be reduced where staff have training in managing stress, stigma, and developing internal coping skills and increased social support, particularly through support groups. The issue of social support has been further examined in the context of volunteer staff [20], and in supervision and peer support associated with 'survival bonding' in the face of terminal AIDS care [43].

A recent study from Milan [8] of 410 infectious diseases nurses surveyed with the MBI and the AIDS Impact Scale [19] also demonstrated that empathic relationships are protective for burnout, and that work stress is tolerated better where there are supportive social rewards. These researchers concluded that prevention of burnout in AIDS care requires more attention given in selection of workers, training to be given in psychological aspects of relationships (with patients and colleagues), clearer definition of staff roles, and groups for support — once again, many lessons in burnout prevention from the pre-AIDS era are being re-learned [44].

An earlier report on the MOMS study [45] suggested that in the current climate of organizational change in the health service in England, the prospects for social support were undermined by staff facing the threat of redundancy or replacement if professional vulnerability was shown. HIV/AIDS and oncology staff reported that they no longer trusted what colleagues might do with such information. A later study qualitatively examining the impact of differing models of staff support in four separate HIV/AIDS care facilities in England [46] has confirmed that lack of trust in colleagues had a material impact on willingness to 'open up' to both colleagues and to staff-support facilitators. An evident confusion over what support is being provided (e.g., emotional counselling or professional monitoring) means that in some settings the provision of staff support may actually increase stress in the workplace [46].

Taking work stress home and home stress to work

Studies are now considering dimensions of work stress and burnout on non-work lives of HIV/AIDS health workers, an area hitherto given scant attention in non-AIDS literature. A recent study from Zambia [47] of 101 HIV/AIDS counsellors revealed that 70 had a relative who had died of AIDS, but few of those surveyed had discussed the illness with the relative. Of those surveyed, 72 worried about their own HIV status, yet 53 did not want to know their own HIV status, and only 24 had

been tested for HIV. In addition, only 27 had ever used a condom in their own sexual lives and, as might be expected in settings where sexual negotiation by women is still unusual, the female counsellors surveyed revealed they could not discuss sex with their partners or with their clients.

A study of the impact of working in HIV/AIDS or oncology on the social and domestic lives of 203 health staff [48] found that friends appear more likely than families of HIV/AIDS staff to be supportive of their work, that HIV/AIDS staff discuss work significantly more often than oncology staff in social settings, and that colleagues are the main source of social contact for staff from both settings. Overall, 44% of staff reported work issues causing active conflict with domestic partners, mainly centring on the domestically intrusive demands and commitments that work in these fields caused. Those interviewed reported that work was responsible for domestic distress up to 90% of the time, just under one-quarter had reported serious relationship difficulties because of work, and one-third had experienced a broken relationship they attributed directly to work. Such findings are not routine even where they are researched — no correlations between work-based stresses and subsequent social or domestic adjustment were found in the recently reported Berlin study [7].

Personality and burnout

The role of personality in burnout has received new impetus with recent research from Italy [10]. Nurses ($n = 139$) and physicians ($n = 55$) completed a range of standardized questionnaires measuring aspects of personality. The researchers found that burnout was correlated with 'ego weakness', not managing others and not managing group situations. The increasingly corroborated finding of elevated burnout scores in younger staff [5,11] and of inexperience being associated with lowered levels of personal accomplishment was also found in this study. However, perhaps the most interesting finding in this study concerned the general lack of MBI subscale correlations with standardized personality variable scores, although more work is clearly needed. This finding endorses the view that staff stress management approaches requiring workers to adapt and change are indicative of inappropriate blaming of individuals who are themselves expressing appropriate responses to unreasonable organizational conditions [49].

The context of caring

Indeed, recognition of the role of organizational structures and of the broader contexts of sex role socialization and expectation in the development of burnout is growing on the vehicle of HIV research [50,51]. A review of the stages of response made by the Drug Abuse Treatment System to HIV/AIDS in New York [50] identified institutional stages of denial, panic and coping as the realities of the HIV pandemic were avoided, recognized and accommodated. However, a potential fourth stage of burnout was also described, where the combined and

unrelenting imperatives of HIV/AIDS responses, care and management could overwhelm services and the personnel within them. The actual experience of the closure of a major peer-led community service for individuals with AIDS in London, 'Frontliners' [52], highlighted the particular vulnerabilities of volunteer and peer-led bodies that struggle to accommodate the burgeoning imperatives and demands placed on them by a grateful public. The three key factors identified in the demise of frontliners were the lack of relevant management experience in those leading the organization, the very rapid expansion of the organization in response to the demands of members and funders, and the transition from self-help (for people with AIDS by people with AIDS) to service provision, undertaken without sufficient research or planning [52]. A vital question for future research is how do so many AIDS service organizations in low resource and developing country contexts manage to survive?

Management of work stress and burnout in HIV/AIDS

Management of burnout and work stress is poorly articulated overall and rarely with the burden of empirical data. Increasingly, however, findings in staff cohorts are being interpreted in ways that provide options for doing something constructive. However, the tension between organizational and individual staff needs may get in the way. It is not surprising that in short-term financial cultures that have moved away from a service delivery ethos of collaboration to internal competition, health service employers appear to have little interest or sympathy for research that reveals them to be poor employers [49]. The following additional paradoxes pertain [11]:

- (1) It is often organizational conditions that generate the stress, whereas it is individual staff who are expected to accommodate and adapt.
- (2) Burnout is the consequence of chronic stress, yet proposed solutions are often acute, involving seminars or workshops lasting only a few days.
- (3) Proposed solutions are often simplistic and formulaic abstractions of clinical processes, applied uncritically to inherently complex, multi-faceted and interactive circumstances and cognitive processes [53].

As noted in a recent review, 'stress management and education cannot substitute for a rational analysis of the institutional and systemic changes necessitated by the growing AIDS health crisis' [27]. Nevertheless, it is clear that suggestions for training offer considerable advantage for reducing staff stress. Untested suggestions for education and training from recent studies include the following:

- (1) Orienting volunteers to have realistic expectations of what they can achieve and to what the organization wants [20];
- (2) Stress management, handling stigma and developing social support through group interventions [25];
- (3) Managing psychological aspects of relationships [8];
- (4) Providing clinical management updates, and multidisciplinary management of psychosocial difficulties and counselling for patients [11];
- (5) Managing interpersonal relationships and group situations [10].

In describing the content of training courses in HIV management for physicians and dentists in Texas, one study [54] identified the essential components of a core curriculum as infection fear and avoidance, homophobia, spouse/partner fear or reluctance, identification with patients, anger, helplessness, grief and burnout, clinical skill development, patient issues of disability, disfigurement, dementia and death, and sexual history-taking. Gallop *et al.* [55] summarized the results of a well-controlled study assessing the inclusion of testimony from people with HIV in training. They found that having a person present with HIV, or a video of them, to be equally helpful.

These suggestions for training concern facilitating communication and sharing of experience. Social support in the workplace is possibly boosted through such interventions [29], although this needs testing. The relationship between provision of staff support, of a social nature or not, and the impact of work stress on home and social life (and vice versa) must be a topic for future research. The need to admit non-work life into work support programmes has recently been both demonstrated [48] and undertaken [25].

A dilemma for health service managers is that staff will only want to use staff support if it is 'safe' to do so and they will not be penalized by colleagues if they admit their vulnerability. It seems that targeting support may help with this, for example, to specific age groups [5,11], although the process then runs the risk of reinforcing staff divisions. Clearly, more work is required to assess the utility of varying support methodologies, of generic transferable concepts and approaches, and of means for measuring outcome. However, an important first step in improving staff compliance is to ask staff what they want from staff support. In her Sydney study, asking staff this question led Bennett [25] to characterize personal burnout prevention strategies that were work-related, those separating work and home lives, and those focusing on individual needs. Studies in England [11,46] have found that staff required support to be accessible when they needed it, a facilitator whose neutrality and expertise they could trust (usually preferring an 'outsider'), a mixture of individual and group support, complete confi-

dentiality with support unlinked to management, management endorsement of support-receiving, and agreed, clear ground rules to clarify the aims of staff support. A consistent difficulty with staff support has been the confusion of emotional support with professional monitoring, along with training in skills development and/or relaxation, and context management [46].

Future directions in characterizing HIV/AIDS burnout

Much of the earlier work in the area of HIV/AIDS on staff stress and burnout featured methodological inadequacies that hindered replicability or generalizability of results [56]. Such difficulties appear to remain in some areas [21], for example, in the context of work on fear of infection, there continues to be a reliance on survey methods and single item measures. What recent work demonstrates, however, is the growing robustness and utility of work in this area of HIV/AIDS care.

There is a need to invest more in providing solid and practical data in this field. In the context of what appears to be a recurrent theme arguing for more theoretically driven burnout research [57,58], the argument is made for the further use of interview and qualitative methods of data gathering to allow health workers themselves to set the agenda on issues of risk perception and other factors that characterize being an HIV/AIDS health worker under stress:

'Too often, health care workers' own perspectives appear to be lost by the manner in which the issues have been framed by researchers' [21].

Clearly, as awareness of the impact of HIV disease on the work capacities and structures in developing countries and non-western cultures emerges [33,34,47,59], the need to consider cultural and organizational factors in development of work stress and in development of stress prevention measures becomes critical. In short, burnout and its prevention needs to be studied in developing countries, where the skills of experienced health staff and community carers cannot easily be replaced.

More research is needed on prospective studies linking health workers' attitudes and beliefs and actual professional behaviour, such as the adoption of universal precautions and avoidance of persons with AIDS. Outcome studies linking staff support to quality of care are needed more than ever. Finally, it is also worth remembering that health care was stressful before HIV appeared — there may be a great deal still to learn from related fields of health care, as long as the same mistakes are not repeated.

References

1. Horstman W, McKusick L: The impact of AIDS on the physician. In *What to do about AIDS?* Edited by McKusick L. Berkeley: University of California Press; 1986:63-74.

2. Treiber FA, Shaw D, Malcolm R: Acquired immunodeficiency syndrome: psychological impact on health personnel. *J Nerv Mental Dis* 1987, 175:496-499.
3. Ross MW, Seeger V: Determinants of reported burnout in health professionals associated with the care of patients with AIDS. *AIDS* 1988, 2:395-397.
4. Rugg D, Schulz SL, Fagan R, Rhodes F: Job related stress among HIV antibody test counsellors. V International Conference on AIDS. Montreal, June 1989 [MDP 43].
5. Bennett L, Michie P, Kippax S: Quantitative analysis of burnout and its associated factors in AIDS nursing. *AIDS Care* 1991, 3:181-192.
6. Kleiber D, Gusy B, Enzmann D, Beerlage I: Causes and prevalence of stress and burnout among health care personnel in the field of AIDS. Presented at VIII International Conference on AIDS/STD World Congress. Amsterdam, July 1992.
7. Kleiber D, Enzmann D, Gusy B: Stress and burnout in AIDS health care: are there special characteristics? In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:115-130.
8. Visintini R, Fossati A, Fontana S, et al.: The measurement of the impact of working with HIV-patients on nurses: reliability, construct and criterion-related validity of the AIDS impact scale. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:93-114.
9. Bellani ML, Protti E, Pezzotta P, et al.: Psychiatric disorders in health care personnel working in AIDS units. IX International Conference on AIDS/IV STD World Congress. Berlin, June 1993 [PO-D21-4045].
10. Bellani ML, Furlani F, Gatti M, et al.: Burnout and related factors among HIV/AIDS health care workers. *AIDS Care* 1995 (in press).
11. Miller D: *Dying to Care?: Occupational Morbidity and Burnout and Preferences for Staff Support in HIV and Oncology Health Care* [Doctoral Thesis]. Nottingham: University of Nottingham; 1995.
12. Maslach C, Jackson SE: *The Maslach Burnout Inventory. Manual* (2nd Edn). Palo Alto: Consulting Psychologists Press; 1986.
13. Plant ML, Plant MA, Foster J: Stress, alcohol, tobacco and illicit drug use amongst nurses: a Scottish study. *J Adv Nursing* 1992, 17:1057-1067.
14. Cooper CL, Davidson M: Sources of stress at work and their relation to stressors in non-working environments. In *Psychosocial Factors at Work and their Relation to Health*. Edited by Kalimo R, el-Batawi MA, Cooper CL. Geneva: World Health Organization; 1987:99-111.
15. van Servellen G, Leake B: Burn-out in hospital nurses: a comparison of acquired immunodeficiency syndrome, oncology, general medical, and intensive care unit nurse samples. *J Professional Nurs* 1993, 9:169-177.
16. Cherniss C: *Staff Burnout: Job Stress in the Human Services*. Beverly Hills, CA: Sage; 1980.
17. Leiter MP: The impact of family resources, control coping, and skill utilisation on the development of burnout: a longitudinal study. *Hum Relations* 1990, 43:1067-1083.
18. Davidson G, Gillies P: Safe working practices and HIV infection: knowledge, attitude, perception of risk, and policy in hospital. *Qual Health Care* 1993, 2:21-26.
19. Bennett L, Kelaher M, Ross MW: The impact of working with HIV/AIDS on health care professionals: development of the AIDS Impact Scale. *Psychol Health Int J* 1994, 9:221-232.
20. Maslanka H: HIV volunteers. In *Health Workers and AIDS*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:151-174.
21. Horsman J, Sheeram P: Health care workers and HIV/AIDS: a critical review of the literature. *Soc Sci Med* 1995 (in press).
22. Morin SF, Batchelor WF: Responding to the psychological crisis of AIDS. *Public Health Rep* 1984, 99:4-9.
23. Christ GH, Weiner LS: Psychosocial issues in AIDS. In *AIDS: Etiology, Diagnosis, Treatment and Prevention*. Edited by DeVita VT, Hellman S, Rosenberg SA. Philadelphia: JB Lippincott; 1985:275-298.
24. Miller D, Brown B: Developing the role of clinical psychology in the context of AIDS. *The Psychologist* 1988, 2:63-66.
25. Bennett L: The Sydney study: interventions to assist responses of health care professionals in HIV/AIDS. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:191-212.
26. Eakin JM, Taylor KM: The psychosocial impact of AIDS on health workers. *AIDS* 1990, 4 (suppl 1):S257-S262.
27. Elfridge GD, St Lawrence JS: The knowledge, attitudes and behaviour of health care professionals regarding HIV and AIDS: current status of the research literature. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:35-60.
28. Epstein RM, Christie M, Frankel R, Rousseau S, Shields C, Suchman AL: Understanding fear of contagion among physicians who care for HIV patients. *Fam Med* 1993, 25:264-268.
29. Cordes CL, Dougherty TW: A review and integration of research on job burnout. *Acad Management Rev* 1993, 18:621-656.
30. Weyant RJ, Simon MS, Bennett ME: Changes in students' attitudes toward HIV infected patients as the students progress through medical school. *Academic Med* 1993, 68:377-379.
31. Gilmore N, Somerville MA: Health care professionals responding to AIDS: ethics, law and human rights. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:361-400.
32. Mann J: Human rights and the new public health. *Int Q J Health Hum Rights* 1995, 1:229-233.
33. Miller D: Stress and coping of HIV/AIDS health care workers: a review and a challenge. VII International Conference on AIDS in Africa. Yaounde, December 1992 [WP103].
34. Ankrah EM: AIDS and the social side of health. *Soc Sci Med* 1991, 32:967-980.
35. Guinan L, McCallum W, Painter L, et al.: Stressors and rewards of being an AIDS emotional-support volunteer: a scale for use by care-givers for people with AIDS. *AIDS Care* 1991, 3:137-150.
36. Sunderland RH, Shelp EE: Supervision solves volunteer 'burnout' problem. IX International Conference on AIDS/IV STD World Congress. Berlin, June 1993 [WS-D16-5].
37. Nesbitt WH, Ross MW, Sunderland RH, Shelp EE: Prediction of grief and HIV/AIDS-related burnout in volunteers. *AIDS Care* 1996 (in press).
38. Calvert GM: Volunteer motivation and retention in an voluntary AIDS service organisation. IX International Conference on AIDS/IV STD World Congress. Berlin, June 1993 [WS-D16-4].
39. Claxton RPR, Burgess AP, Catalan J: Motivational factors and psychosocial stress in emotional support volunteers (buddies) for people living with AIDS. IX International Conference AIDS/IV STD World Congress. Berlin, July 1993 [PO-D21-4064].
40. Constable JF, Russell DW: The effect of social support and the work environment upon burnout among nurses. *J Hum Stress* 1986, 12:20-26.
41. Moos RH, Insel PM (Eds): *Combined Preliminary Manual, Family Work and Group Environmental Scales*. Palo Alto, CA: Consulting Psychologists Press; 1974.
42. House JS, Wells JA: Occupational stress, social support, and health. In *Reducing Occupational Stress* [US Department of Health, Education and Welfare Publication No. (NIOSH)]. Edited by McLean G, Black G, Colligan M. Washington, DC: Government Printing Office; 1978:8-29,78-243.
43. Wade K, Perlman Simon E: Survival bonding: a response to stress and work with AIDS. *Social Work Health Care* 1993, 19:77-89.
44. Schaufeli WB, Maslach C, Marek T (Eds): *Professional Burnout: Recent Developments in Theory and Research*. Washington, DC: Taylor & Francis; 1993.
45. Miller D, Gillies P, Elliott C: Successful staff burnout prevention: lessons from six major UK HIV/AIDS treatment sites. X International Conference on AIDS. Yokohama, August 1994 [abstract 1405].
46. Miller D, Gillies P, Elliott C: *Prevention of Occupational Morbidity and Burnout in Management of HIV Infection and Disease: Final Report*. London: Department of Health; 1995.
47. Baggaley R, Sulwe J, Kelly M, Ndori Macmillan M, Godfrey-Faussett P: HIV counsellors' knowledge, attitudes and vulnerabilities to HIV in Lusaka Zambia 1994. *AIDS Care* 1996 (in press).
48. Miller D, Gillies P: Is there life after work: experiences of HIV and oncology health staff. *AIDS Care* 1996 (in press).
49. Halton W: Institutional stress on providers in health and education. *Psychodynamic Counselling* 1995, 1:187-198.
50. Des Jarlais DC: Stages in the response of the Drug Abuse Treatment System to the AIDS epidemic in New York City. *J Drug Issues* 1990, 20:335-347.
51. Roth NL: Structuring burnout: interactions among HIV/AIDS health workers, their clients, organisations and society. In *Health*

- Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:73-92.
52. Moreland L, Legg S: *Managing and Funding AIDS Organisations*. London: Department of Health/Compass Partnership; 1991.
 53. Reynolds S, Briner RB: Stress management at work: with whom, for whom and to what ends? *Br J Guidance Counselling* 1994, 22:75-89.
 54. Brimlow D: Training to prevent burnout: HIV/AIDS programmes for physicians and dentists. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:247-258.
 55. Gallop R, Taerk G, Lancee W, et al.: A randomised trial of group interventions for hospital staff caring for persons with AIDS. *AIDS Care* 1992, 4:177-185.
 56. Miller D: Occupational morbidity and burnout: lessons and warnings for HIV/AIDS carers. *Int Rev Psychiatry* 1991, 3:439-449.
 57. Schaufeli WB, Enzmann D, Girault N: Measurement of burnout: a review. In *Professional Burnout: Recent Developments in Theory and Research*. Edited by Schaufeli WB, Maslach C, Marek T. Washington, DC: Taylor & Francis; 1993:199-215.
 58. Maslach CH, Ozer E: Theoretical issues related to burnout in AIDS health workers. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:1-14.
 59. Kalibaba S: Impact of HIV/AIDS caregiving on health markers in Uganda and other parts of sub-Saharan Africa. In *Health Workers and AIDS: Research, Intervention and Current Issues in Burnout and Response*. Edited by Bennett L, Miller D, Ross MW. Reading: Harwood Academic Press; 1995:285-306.

9

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



REVIEWS

Are our information, education and communication-based interventions too superficial?

Ian Clarke MB MSC DTM&H

Co-ordinator for an operational research programme into the community's response to AIDS in Luweero, Uganda

TROPICAL DOCTOR, 1995, 25, 167-170

INTRODUCTION

Those of us who have had experience of working in the field of AIDS in developing countries have acquired considerable knowledge about the problems of combating this epidemic. Unfortunately, we are less knowledgeable about real solutions. An academic paper about the limited impact of behavioural intervention often concludes that more research is required.

In East and Central Africa the epidemic has moved beyond the stage where it is effective to target high risk groups. Everyone who is sexually active is at high risk. Interesting current research has highlighted the increased transmissibility of HIV in association with other sexually transmitted diseases (STDs). However, behavioural interventions have been difficult to evaluate¹ and there is little hard evidence that they are effective. There is now growing recognition in some quarters that an effective approach to slowing the AIDS epidemic needs to be multisectoral and broad based². The magic bullet of the pure medical intervention looks unlikely, though it may have a part to play as part of a broader approach. AIDS can no longer be considered the exclusive province of epidemiologists or virologists³, even though they have contributed more than anyone to our understanding of the epidemic.

There are many factors which have contributed to the rapid spread of AIDS in developing countries not least of which is the lack of development itself. People in countries such as Uganda are very aware of the effects of AIDS, most people having had immediate family members who have been affected. However, they are also preoccupied with the immediate constraints and necessities of life. Even though the consequences of AIDS are devastating, they are a distant effect of a current action. When current action is necessary, as it may be in the case of a woman who needs to obtain a little financial help for the necessities of life, or for a young person who needs to prove their potency and 'normality', then the possibility of AIDS in several years time does not appear so important.

BEHAVIOURAL INTERVENTIONS

One problem with many behavioural interventions seems to be that they address the problems superficially. For example, imparting information to the individual regarding the biological transmission of the HIV virus, while necessary, is inadequate on its own. Many of the current intervention programmes revolve around counselling and testing⁴, the provision of supportive groups¹, and the provision of care for those who are infected. AIDS information given through community groups, hospitals, churches, mosques and schools is also being promoted. Other encouraging interventions involve the promotion of condoms⁵ through social marketing, and pilot studies on the reduction of STDs. However, I would like to concentrate on the information, education and communication based initiatives (IEC). These initiatives are all very necessary, so why have I made the criticism that they are superficial. The problem lies not in the interventions themselves. In the analogy of seed and soil - as seed they are legitimate. However, whether the seed will germinate and bring forth fruit depends on the soil in which it is sown. Hence a campaign of health information may be effective among the gay community in San Francisco, but may be totally ineffective among rural women in Uganda.

BACKGROUND

So what is the background in which these seeds are being sown? My own experience is in rural Uganda, so I will draw from that experience. In Uganda, although the urban areas have had the highest prevalence of HIV, 80% of the people live in the

Correspondence to: Dr Ian Clarke, 13 Fox Road, Holmer Green, High Wycombe, Buckinghamshire HP15 6SE, UK

rural areas⁶. When I refer to Ugandan traditions I will mainly, but not exclusively, be referring to Baganda traditions, as the area in which I worked (The Luweero Triangle) was about 60% Baganda⁷. It may not be possible to generalize from the traditions of one nation to another. However, the same principle applies, i.e., that in carrying out behavioural interventions one needs to look beyond the simple solutions to see what are the underlying motivating and constraining factors in the culture.

THE FAMILY

The family structure in Uganda is the extended family. The extended family has many admirable characteristics, one of which is that it is extendible, and therefore it has been called on to absorb the children of other family members who have died of AIDS. One wonders how Africa would cope if the extended family network did not exist. There would simply not be the resources for governments to provide institutional care. Many aid agencies have directed their efforts to support the extended family as they absorb this ever increasing burden due to AIDS. A side effect of the increased demands on the extended family is that less attention can be given to the individual members. The African family has traditionally placed value on the children learning proper manners and learning to fulfil their duties in the clan⁸. It has not necessarily placed a high value on close relationships and good communication within those relationships. Since the clan is important, the girls are supposed to get their sex education from their father's sister. The boys by contrast are supposed to find out for themselves and there is no particular provision for them to receive sex education within the family. Parents do not have a great sense of responsibility to communicate with their children on such subjects as sex education.

Traditionally, it is important that a man is potent and can perform well when he takes his official wife. If a husband cannot fulfil his conjugal rights on the wedding night the marriage is declared nullified. It is the responsibility of the girl's aunt to check that everything has been satisfactory. Young men are aware of the traditions and feel under some pressure to ensure that they do not fail. The result is that the boys start to experiment when they are sexually active in order to ensure their normality. When starting out they generally look for a younger girl in case they get laughed at, hence the age of first sex is younger in the girls than the boys.

It is important in Ugandan culture that the girls learn what is expected of them in terms of looking after a future husband and a home. Thus, they become the water carriers, the house cleaners and the child-minders. As their parents are simply giving them a good upbringing they do not owe them any thanks for these duties. However, it can be a hard existence for a young girl who longs for a sense of appreciation, and it is easier to find this outside the family. This stage coincides with the target age group in which young men are looking for willing partners.

Young girls in the village also have another problem. They need money to buy the small necessities of life, such as a pair of knickers and handkerchiefs. Who can they turn to for the cash? Their mother provides food from the garden, but it is their father who has the cash. The African father is an aloof figure who must keep his distance in order to preserve respect. He cannot be seen to be on familiar terms with his children, otherwise they might abuse the privilege and not respect him. It would be unheard of culturally for a daughter to ask her father for money for such things. So to whom does she turn? Once again she goes outside the family. A young man will be quite prepared to make the investment for the knickers and handkerchiefs and thus show his appreciation for a willing partner.

These illustrations of pressures on the family and traditions demonstrate precipitating factors turning young people towards early sex. AIDS education which seeks to encourage young people to delay their first sexual encounter must have an awareness of the underlying issues, and seek to resolve them. Health education which simply warns of the dangers of AIDS is in competition with the more powerful immediate needs and pressures of the culture.

MONEY AND LOVE

Another area is the relationship of money to sex. It is easy for someone from a western civilization to be judgmental regarding 'commercial sex'. However, it is unlikely that Ugandans take the same perspective. In Uganda there is a traditional proverb.

Obwavu tebukumanyisa akwagala [literally - poverty cannot make known a lover].

As it was explained to me, 'no money no love'. In other words, it is not possible for a man to show his love to a woman without showing some material

appreciation. If he cannot do this, then he cannot really love the person. 'A poor man cannot be a lover.' What does this attitude do to our concept of commercial sex? It turns it on its head. There is no such thing as love for the sake of the relationship. In Ugandan terms, that love has to be expressed tangibly in the form of material provision.

THE TRADITIONAL VIRTUE OF SUBMISSION IN A UGANDAN WOMAN

Another value which is highly prized in a woman is submission⁹. A Ugandan girl who is well brought up is taught that she must please her man and be compliant and submissive. As some of the young girls have said to us, 'We have been brought up to believe that we should please a man, therefore it is not natural for us to refuse if a man asks us for sex'.

In fact, it is downright embarrassing for the man. Hence, if the girl is going to refuse, the onus is on her to do it in such a way that he will not know that he has been refused, and she will need to sidestep the issue. Otherwise he will feel put down by a woman who obviously does not possess the quality of submissiveness, and it will be his duty to warn other men that she would not make a good wife. This factor gives a new perspective to the concept of sexual harassment.

AIDS AND CULTURAL VALUES

The system of material expression of love by a man and submission by a woman meets the needs of both men and women. The man is able to have his sexual needs met and the woman her financial needs, both in a manner which is dignified and meaningful. However, with the advent of AIDS, a new message has gone out, i.e. that refusal on the part of the woman is good, and sex for material benefit is bad. Society is being asked to turn traditional values on their head, and although people may pay lip service to the new value system, there may be no fundamental adjustment in the traditional approach.

AIDS information, health education, attempts to increase the age of first sexual encounter, to dissociate sex from material gain and to make women financially independent are all good ideals. However, they will not work unless they address the reasons and traditions which are behind this behaviour. In asking people to change, one is asking a great deal, as one is asking them to change their culture! There is, however, no question about the desirability of changing cultural attitudes since if AIDS continues unabated, in a few decades there may be no culture left to change.

ADDRESSING THE ISSUES WITHIN THE FAMILY

Much AIDS education is aimed at the sexually active couple. However, perhaps it is the family which should be targeted first in order to build in a new set of values. If the young girls were able to have their needs for self worth and appreciation met within the family, they would not need to turn outside the family to boyfriends. If their needs for the small necessities were understood and catered for within the family, they would not be so susceptible to sexual advances. If there was real communication within the family on subjects such as sex education, the whole area could be demystified and the need to experiment removed.

CONCLUSION

None of these issues are straightforward. However, until discussion is initiated at this level, people will continue to pay lip service to the right answers, while holding to traditions and practices which are making change very difficult. There is a great need to address these issues openly, but they are generally not dealt with at all. Even in schools sex education is superficial, as parents, church leaders and teachers are wary of sex education for their own reasons. Parents because they are afraid that knowing the facts will actually encourage promiscuity; teachers because male teachers may abuse the traditional attitude of women to extract sexual favours from a student; and the church leaders because they have reservations about sexual issues being discussed with young people, and are afraid that young people will be introduced to condoms.

While we continue to facilitate such prejudices by dealing with these issues superficially, education will be kept on a theoretical level with minimal effect on behavioural change. There is an increasing willingness among many to deal with the real issues and such willingness needs to be tapped, bypassing those for whom dealing with such subjects is too delicate a matter.

AIDS information and education must aim to get people talking about family relationships, the needs of young people, traditional expectations, attitudes regarding submission and money, and the role of parents in meeting their needs. It is easy to tell people what they should do, but prescriptive orientated AIDS education will achieve little. Going back to the basics of building good family relationships where there is communication, and children have their needs met within the family, is a start. Being prepared to deal with some of the

sacred cows of tradition, such as the high value placed on girls being taught to be submissive to men, is another important step. The recognition that love is expressed through financial provision, and the ensuring, therefore, that the financial provision for the necessities of life should be the responsibility of the family, would be a further vital step. None of these things in themselves will stop the AIDS epidemic, but they will at least create a level playing field for young people to make an informed choice about the risks of multiple sex relationships.

ACKNOWLEDGEMENTS

My thanks to Moses Ssekidde, the Kikamulo AIDS Control Committee, and the community health workers of Kiwoko Hospital Community Based Health-care Programme for their insights, and all their work in gathering information from the community.

REFERENCES

1 Assessing prevention achievements and failures: the

importance of monitoring and evaluation [Editorial]. *AIDS Hlth Prom Exch* 1993;4:1-3

- 2 Zwi A, Cabral J. Identifying high risk situations for preventing AIDS. *BMJ* 1991;303:1527-9
- 3 Packard R, Epstein P. Epidemiologists, social scientists and the structure of medical research on AIDS in Africa. *Soc Sci Med* 1991;7:771-94
- 4 Muller O, Barugahare L, Schwartzlander B. HIV prevalence attitudes and behaviour in clients in a confidential HIV testing and counselling centre in Uganda. *AIDS* 1992;6:869-74
- 5 Hanenberg RS, Rojanapithayakorn W, Kunasol P, Sokal DC. Impact of Thailand's HIV-control programme as indicated by the decline of sexually transmitted diseases. *Lancet* 1994;334:243-5
- 6 Statistics Department. *1991 Population and Housing Census*. Entebbe: Ministry of Planning and Economic Development, 1991
- 7 Clarke I. *Investigation Of Factors Related To the Spread Of AIDS In a Rural Community In Uganda*. London: LSHTM, 1994
- 8 Karigire SR. *A Political History of Uganda*. Nairobi: Heinemann Educational Books, 1980
- 9 Kisekka MN, Southwold M. The Buganda of Central Uganda. In: Molnos A, ed. *Culture Source Materials For Population Planning In East Africa*. Nairobi: East African Publishing House, 1972. 167-81

1996 FRED L SOPER AWARD

The Pan American Health and Education Foundation (PAHEF) is pleased to announce the 1996 Fred L Soper Award for papers of excellence in the health sciences of significance in the field of inter-American health. The Award is given in recognition of D Soper, Director of the Pan American Health Organization from 1947 to 1959, who for 50 years made outstanding contributions to health in the Americas.

Eligibility is still limited to papers by authors whose principal affiliation is with Latin American and Caribbean institutions, published during calendar 1995. However, papers may now be accepted if they have appeared in any scientific journal listed in the *Index Medicus*, no matter where located, or in the official journals of the Pan American Health Organization. All submissions must be received by 31 March 1996 at the following address:

Executive Secretary
PAHEF
525 23rd Street NW
Washington, DC 20037
USA

10

MATERIAL ON HIV/AIDS

SENT BY

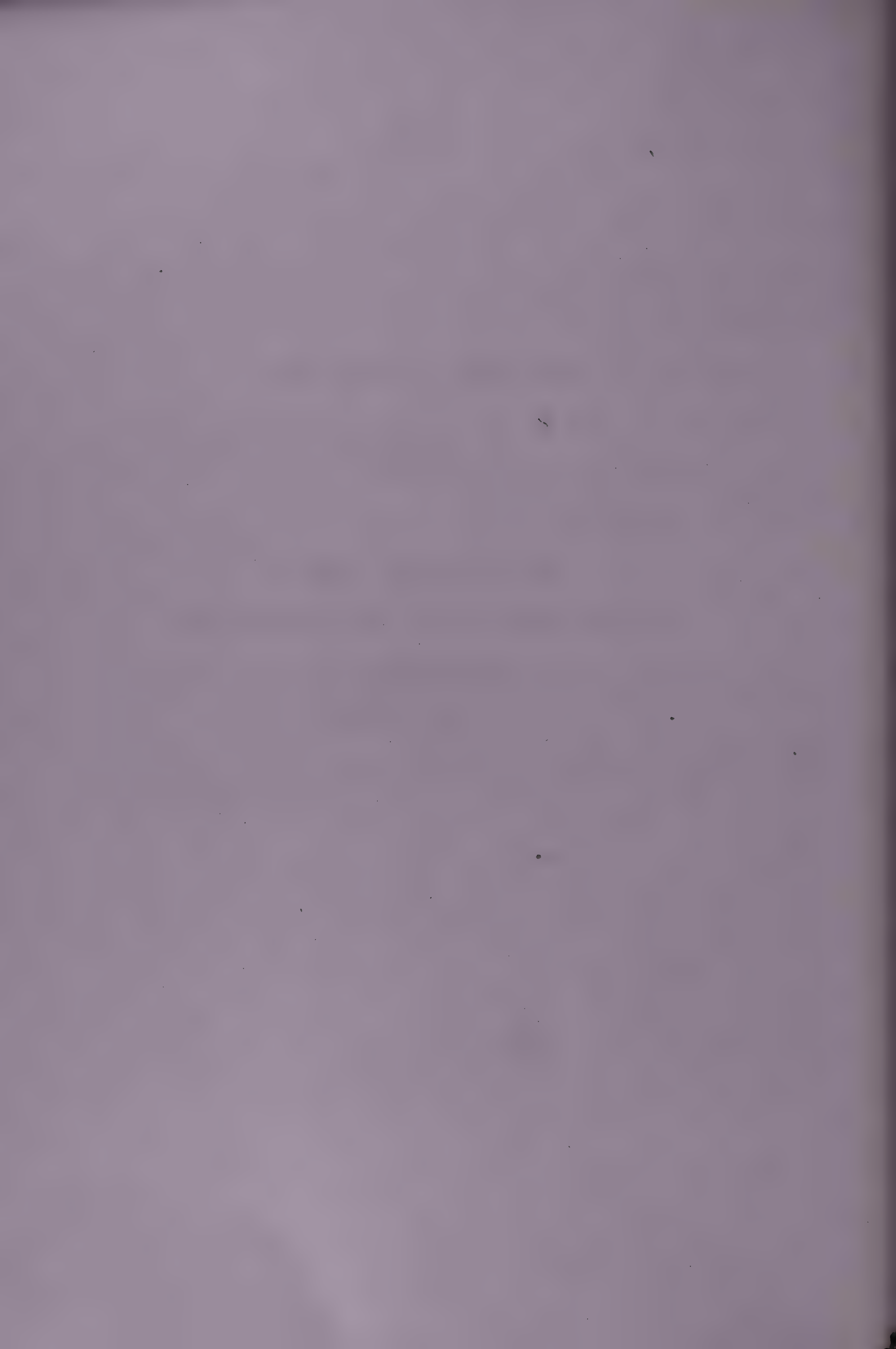
MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



13.4.1.156

SCHÖFLICHES HILFSWERK
MISEREOR E. V.
THE GERMAN CATHOLIC
BISHOPS' ORGANISATION
FOR DEVELOPMENT
COOPERATION

Postal address: POSTFACH 1450
D-52015 AACHEN
GERMANY

Office address: MOZARTSTRASSE 9
D-52064 AACHEN
GERMANY

MISEREOR

PHONE: +49/241/4420

FAX: +49/241/442188

CAMPAIGN AGAINST HUNGER
AND DISEASE IN THE WORLD

HIV/AIDS and Church Development Work

(Synopsis)

*Drawn up in cooperation with the AIDS and International Health Department,
Medical Mission Institute, Würzburg, Germany*

1. The HIV/AIDS Pandemic

The HIV/AIDS pandemic is developing into a tragedy for all of humanity. In the second decade of its global spread it is undermining all of the progress, opportunities and options achieved towards development worldwide. Countless individuals and communities suffer not only immense physical and mental pain from HIV/AIDS but also increased deprivation and social discrimination. Cause and effect reinforce one another reciprocally in an ever-escalating spiral. The structural economic crises and the processes of social disintegration coming to a head in many parts of the world provide fertile soil for the rapid spread of HIV infection.

The majority of those infected live in developing countries (1994: 84%; the projection for 2000: >90%). The disadvantaged, the uprooted and those deprived of their rights are particularly vulnerable in any society. The youth and the young adults are especially affected, primarily in urban areas but increasingly so in rural areas as well. AIDS leads to a demographic shift of the productive and non-productive age groups within a society. The fact that women and girls are disadvantaged means that they are being infected in ever-increasing numbers. Children too are affected by HIV and AIDS, directly and indirectly.

Church organisations in development cooperation must take up the challenge, along with their partners and those affected, to help find an answer. Christians consider it their duty to uphold human dignity and to call for action free of prejudice and discrimination. That entails giving hope, combatting the social causes of HIV/AIDS and easing the effects.

The major channels of HI virus transmission are: a) sexual intercourse (70-80%), b) mother-to-child transmission (5-10% of all cases), c) blood transfusions (3-5% of all cases), and d) intravenous drug use (1-3%). Someone infected with HIV remains infectious for the rest of his/her life.

AIDS is the final stage of HIV infection. On average it is reached after a period of 8 to 10 years. The most frequent interaction between AIDS and other infectious diseases is with tuberculosis and with other sexually transmitted diseases.

There is no curative treatment for HIV/AIDS in sight for the foreseeable future. Licensing of an effective vaccine is not to be expected before the turn of the century. It is also questionable whether future medical answers will be available in a form that will make them accessible to the majority of those stricken in developing countries.

The WHO assumes that, since the beginning of the pandemic, 18.5 million people worldwide have been infected with the HI virus (figures for mid 1995). According to its estimates one out of 250 adults and almost 1.5 million children as well were HIV carriers worldwide in 1993. At present there are 6,000 new infections daily. Conservative WHO estimates predict that worldwide there will be at least 30-40 million people infected with HIV by the year 2000.

By 30 June 1995 there were 1,169,871 cases of AIDS reported to the WHO. However, it is estimated that there are a total of 4.5 million people already suffering from AIDS (one-fifth of them children). In many places in developing countries AIDS is now the major cause of death among the age group of sexually active adults.

2. The Basic Concepts for Support

MISEREOR applies the following principles for its support of AIDS initiatives:

- * Respect for the dignity and rights of the human being are of foremost importance.
- * Any approach used in HIV/AIDS work must be adapted to the economic and cultural conditions in the particular society.
- * Indigenous coping mechanisms will be promoted and supported.
- * HIV/AIDS initiatives must aim at social equality for both sexes and secure the women's right to self-determination.
- * Social learning is of priority.
- * Individuals and groups will be supported in their efforts to become self-reliant, and given education and training to enable them to become active in a social and political sense.
- * HIV/AIDS is not an isolated development problem. It should be integrated into a broad framework of cross-sectoral development work.
- * HIV/AIDS work is to aim at solutions which are appropriate to the phases of the epidemic.
- * HIV/AIDS work is particularly worthwhile when it addresses the spiritual and pastoral needs of those affected.
- * HIV/AIDS activities call for long-term monitoring and support on the part of the donor and executing agencies and the Local Churches.

3. Individual Activities and Trends

HIV/AIDS activities profit from an atmosphere where AIDS is visible, discrimination is reduced and eliminated, and there is reason to hope that it will be possible to avoid HIV infection.

Various types of initiatives addressing AIDS issues reinforce one another. Which type of AIDS strategy is worthwhile depends on socio-cultural and socio-economic factors and what stage the regional epidemic has reached. The following have been recognised as effective individual steps in the field of AIDS work:

- human rights programmes, advocacy;
- programmes to strengthen the status of women;
- health education programmes;
- providing care for the infected/ill and comfort in the final stages;
- the control of opportunistic infections, especially tuberculosis;
- the control of other sexually transmitted diseases;
- HIV test programmes to ensure the safety of blood transfusions;
- providing education on responsible sexual behaviour and information on protection against infection;
- programmes to alleviate the effects of AIDS on families.

Definite trends are becoming clear in a number of areas. Early and frank sex education beginning before the onset of sexual activity if possible clearly reduces the spread of HIV. The need for care from counselling to nursing will rise drastically worldwide. More than a million new cases of AIDS per year are to be expected by the turn of the century. One possible way of relieving the pressure on health care services and ensuring their continued function is the promotion of home care. Feasible options to reduce the costs of counselling and care without reducing their quality seem to be emerging.

HIV/AIDS work must in future clearly go beyond measures against what is considered risk behaviour and eliminate the reasons for such behaviour. That is to say, questions of human rights and development will be of increasing importance.

The general criteria for MISEREOR's support are based on the CIWG/AFNG funding guidelines worked out by CARITAS and CIDSE member organisations (see below). Long-term involvement is called for and the readiness of donor organisations to provide support for a number of selected activities whose costs the target groups or the Local Churches in the developing countries cannot cover on their own. On the other hand, this catalogue excludes certain activities which cannot be supported by donor organisations within the Church context.

The gap between the resources required and those available will become even wider in future. The increasingly scarce funds available for development work must therefore be used more effectively and efficiently. Better coordination and sharing of responsibility are called for. But MISEREOR also recognises the challenge to work for international solidarity and to increase public awareness in Germany for development problems which are becoming obvious as a result of the HIV/AIDS pandemic.

4. Guidelines and Minimal Criteria for Aids Project Proposals

drawn up by the Caritas Internationalis Working Group on AIDS (CIWG) and the AIDS Funding Network Group (AFNG) of CIDSE member agencies (16 May 1994) - please see additional photocopies.

11

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

All children in developing countries will be affected by AIDS, not just orphans.

The HIV/AIDS epidemic will transform the situation of children in the developing world through:

Direct and indirect increases in child mortality;

Rising rates of adolescent HIV and widespread orphaning; the deterioration of societal and community conditions due to adult mortality.

Childhood is a long-term investment in the development of a human being.

Societies must be able to divert resources from meeting their immediate needs in order to invest in future generations. The most disturbing aspect of AIDS is the manner in which it forces families, communities and entire societies into a short-term coping mode, forfeiting the physical, social and other developmental needs of their children.

Between 10% and 18% of reported AIDS cases in southern African countries are children aged 0 - 4 years.

As the inevitable cause of a large number of child deaths, AIDS is different from other communicable diseases. Projections of the impact of AIDS upon child mortality rates (CMR) in sub-Saharan Africa (see graph) are based upon estimated 25% - 40% vertical transmission rates.

It is anticipated that reduced household food production levels, overtaxed national health systems, and the loss of key community health workers and services will also contribute to reversing the progress of recent decades in Africa and elsewhere. By precipi-

tating additional deaths, the effect of AIDS upon child mortality rates will be most marked in relatively low CMR countries such as Zimbabwe, Kenya and South Africa. Similar effects can be anticipated in south Asia.

It is striking how little attention has been focussed upon issues surrounding the burden of care for paediatric AIDS cases. With rising general population AIDS incidence, some of the publicised

age group. The WHO has estimated that in many countries, the age group 15 - 24 years accounts for 60% of all new infections. A disturbing prospect is that as fundamental family and social frameworks erode, due to AIDS-related adult mortality, children may engage in the very high-risk behaviours that lead to infection.

WHO has projected that by 1999, 5 - 10m children aged 10 years or less worldwide will have lost their mothers or both parents to AIDS. Much has been written concerning the expanding crisis of AIDS orphanhood.

However, caution must be exercised in drawing general lessons from the community coping strategies of rural Uganda, Zimbabwe and Tanzania for application in urban Thailand or rural India.

More socially-fragmented societies may be much more vulnerable to the disruptions of AIDS. Despite years of war and economic decline, Ugandan communities, characterised by strong kinships and traditional networks, have stretched their resources to meet the needs of orphans. We must be prepared for a reality that, in late epidemic and endemic phases, conditions for orphans could be far worse in economically better-off urbanised regions or rural areas with diminished patterns of social obligation and support.

The focus upon orphans has distracted the development community from the threats posed for all children in AIDS affected societies. The impact of AIDS through time upon the individual household has been well documented. The combination of medical expenses, reduced income and

lower agricultural productivity gradually deprive the surviving children of nutrition, nurture and education. It is girl orphans who are invariably the first to drop out of school, often burdened by a disproportionate of household work, and subject to the pressures of sexual exploitation.

But AIDS affects entire communities and societies. Other households' resources will be stretched while absorbing orphans. Many of the key players in the development process — teachers, village health workers, agricultural extension workers — will be lost to AIDS. Coping at national levels threatens to draw precious resources from budgets which address the needs of children. National health systems are already overtaxed by AIDS cases. Will they be able to maintain support to child survival programmes?

AIDS' scale of impact upon children represents more than a multiplication of millions of individual cases. While wars have had major demographic effects upon male adult populations, AIDS will be unique as an eliminator of a high proportion of the very population critical to child development, sustenance and education — both male and female.

Broadly, the effects upon children of this slowly evolving disaster can be summarized as due to:

- decline of material and financial resources;
- loss of human resources;
- loss of certitude.

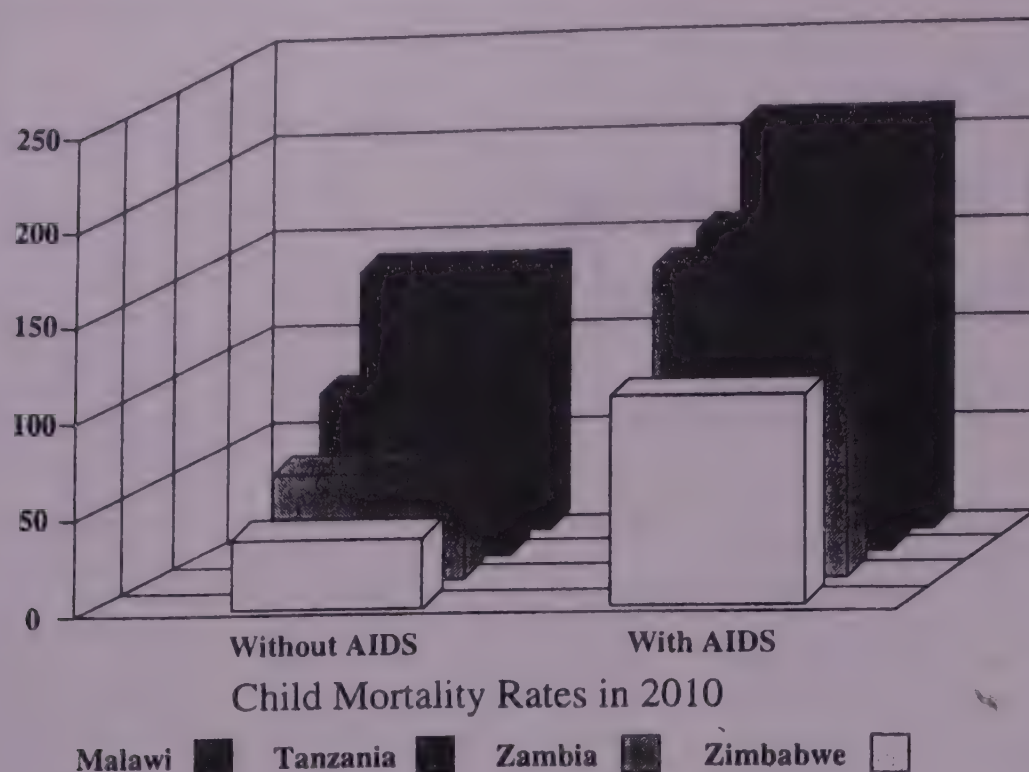
AIDS-affected economies are already suffering due to manpower losses and reduced productivity caused by increased absenteeism. Much of disposable income is eaten up by medical and funeral costs. Loss of remittances from migrants and reduced local production affects an entire community, diminishing opportunities for its children. The resources available for community level services are diminishing, both from governments' budgets and from local

by Dr David A. Goldenberg, Senior Adviser for Programme Policy, Plan International

problems of stigmatisation should be reduced.

At the Nyumbani Children's Home in Nairobi, 'the process of returning those babies who prove to be HIV-infected to their families is usually very slow and often impossible' (UNICEF 1994). Tragically, there is nothing new about ill children in the developing world, but AIDS will drastically reduce the number of their potential adult care-givers within kinship networks and communities. And, of course, the very communities which will most need to organise to extend care to ill children, will be the least able to provide it.

Adolescent children in Africa and Asia are being doubly victimised by AIDS. They are increasingly subject to sexual exploitation (in the misguided belief that they are less likely to be infected) and consequently infected in increasing numbers. Despite some recent encouraging news from one Uganda study (see *AIDS Analysis Vol.5 (5)*), the most rapid increase in infection rates in Africa has been in the youngest



contribution. The most often voiced concern regarding orphans is for their continued education. But even if children can afford school fees, the quality of education is sure to deteriorate even further. How will other local services be affected? Will clinics be staffed and stocked?

Human resources comprise both labour and skills. The development process is built upon surplus labour availability for organisation, project participation and training. Anticipated labour shortages at both household and community levels will threaten this process. Perhaps even more critical is the danger that skills and knowledge may not be transferred to the next generation.

As orphan households reduce agricultural inputs and cope with a shortage of labour, they face real insecurity. But communities as a whole will be challenged by overall reduced agricultural production and the loss of agricultural skills. 'More and more frequently, particularly in rural areas, orphans...find themselves alone and incapable of producing on their small plot of land, which otherwise would assure their subsistence.

The mastering of survival skills is a long process which demands knowledge of the entire chain of production: thus a child who knows the harvest well, but who

cannot plant will be incapable of surviving autonomously'.

With care-takers either lost or overburdened, 'youths are being deprived of family life education which is instrumental in establishing a code of conduct between men and women and husbands and wives.' Africa's orphan generation faces the loss of its childhood as it must prematurely care for sick parents and siblings while missing out on key processes of socialisation and development. What kind of adults will this produce?

Children are often the first to detect the symptoms of AIDS in their parents. They must experience the trauma of a series of losses in their immediate and extended families. This may be followed by dislocations, the split-up of siblings. These compounded losses constitute severe psychological trauma and this may constitute the most severe challenge for community responses to the needs of orphans. However, other children who experience these losses at a greater distance will quite possibly develop a loss of certitude in the predictability and the reliability of the basic social arrangements. Can any relationship be secure?

During the next few years, we need to learn much more about the care and support of orphans in a wider variety of social settings. In particular we must focus attention upon how their psychological needs can be met at the community level. We must also expand our notions of the impact of AIDS beyond the orphan population to understand how entire generations of children with parents will also be affected. ■

For references contact Dr Goldenberg, fax: (+1401) 467-0604

Impact on children in AIDS affected communities

ISSUES	NON-ORPHANS	ORPHANS
Subsistence	Effects of general economic decline	Loss of income: dangers to tenure rights
Food Sufficiency	Reduced community availability	Food insecurity
Labour Demands	Possible effect in households absorbing orphans	Increased burden
Shelter	Possible crowding due to absorption of orphans	Deterioration and possible loss: inheritance threatened
Basic services	Reduced quality	Reduced access
Health services	Reduced quality	Loss of access
Vulnerability to HIV	Vulnerability to general younger age sexual exploitation	Extreme vulnerability to sexual exploitation
Education	Reduced quality	Loss of access
Life Skills	Loss of community mentors	Loss of parental mentors
Psychological	Secondary trauma	Trauma due to loss
Developmental	Social anxiety	Deprived socialisation and lack of role models
Identity and Status	None	Possible loss of kin and community membership

12

MATERIAL ON HIV/AIDS

SENT BY

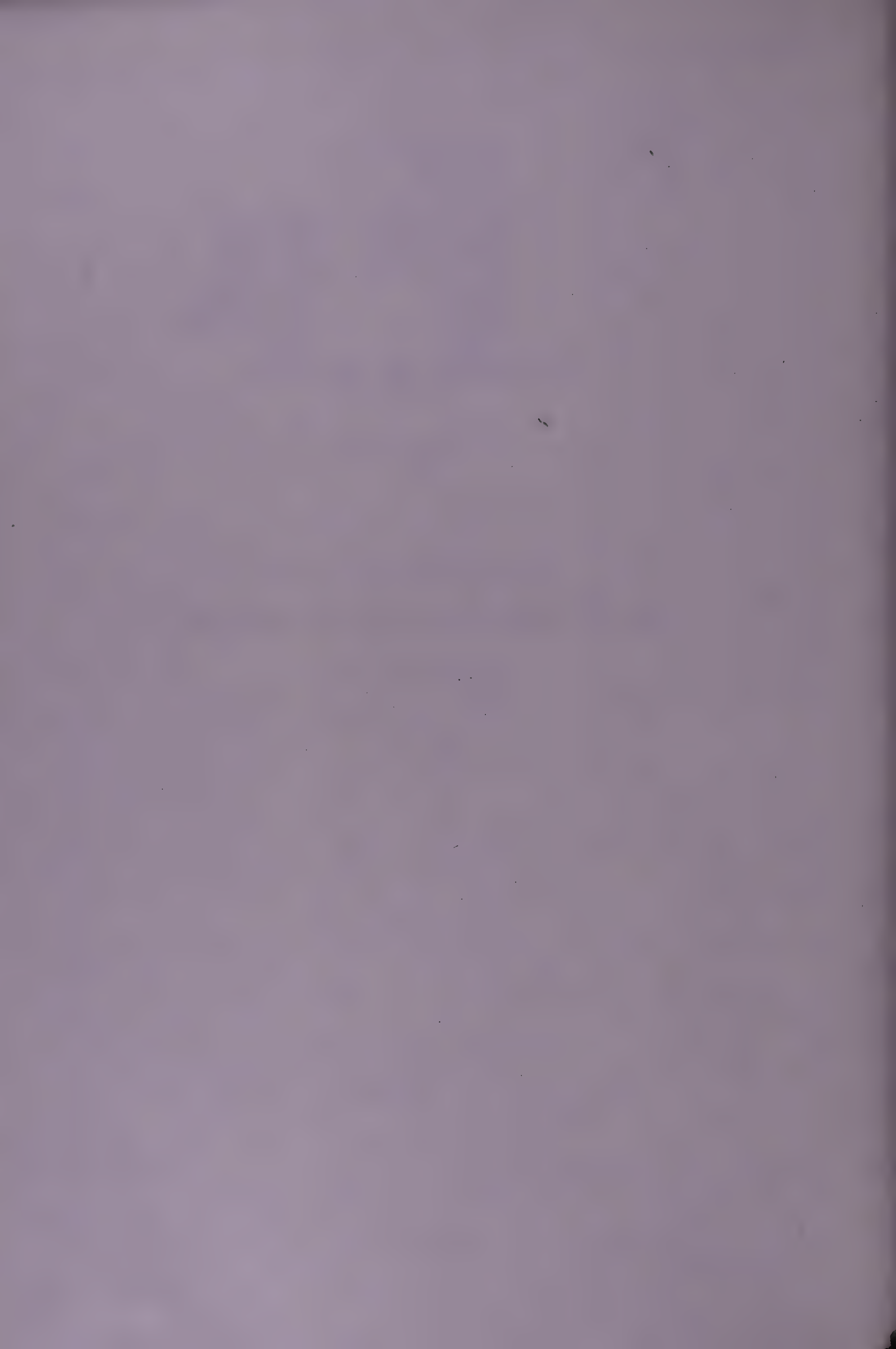
MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY



11.5.4.1.13

AIDS health promotion for youth. Conceptual framework and practical implications

PETER FRANZKOWIAK

Fachhochschule Rheinland-Pfalz, Abt. Koblenz, Fachbereich Sozialarbeit, Koblenz, Germany

EBERHARD WENZEL

Training Associates Philippines, Pasay City, Metro Manila, Philippines

SUMMARY

As the AIDS epidemic continues to expand and as there is no substantial hope for curative treatment, prevention remains the only tool to cope with the threat of HIV transmission and AIDS. This article presents a conceptual framework and detailed guidelines for the planning, implementation and evaluation of AIDS health promotion for youth. The framework focuses on basic principles of health promotion and refers to the

living conditions and lifestyles of youth being of relevance for the development of gender roles and sexual behaviour. Community organization plays a crucial role for AIDS health promotion for youth. Only comprehensive approaches taking account of social and cultural conditions present an adequate arena for successful AIDS health promotion.

Key words: AIDS; community organization; sexual behaviour

INTRODUCTION

The global epidemic of HIV infection remains dynamic and is continuing to expand (Mann *et al.*, 1992; Smallman-Raynor *et al.*, 1992). At the beginning of the 1980s only about 100 000 persons worldwide were infected with HIV. Since then, more than 13 million men, women, and children have become infected. This cumulative total includes more than one million persons who were infected with HIV during the first 6 months of 1992 alone. Nearly two-thirds of these live in Sub-Saharan Africa, 20% in the Americas, and about 15% in Europe, Asia and Oceania. In 1992, the World Health Organization (WHO) estimated the actual cumulative global total of AIDS cases at over one million people.

AIDS constitutes a worldwide problem of major proportions, affecting developed and developing countries. Until the end of this decade, about three times more HIV infections will occur than had occurred during the 1980s.

The vast majority of new HIV infections would be preventable by globally and nationally coordinated efforts. When the AIDS epidemic was first recognized, a high prevalence of HIV infection was found among specific groups: homosexual and bisexual men, users of injectable drugs, and hemophiliacs. Nowadays, it is no longer appropriate to focus on *high-risk groups*, as the epidemic has contaminated all kinds of population groups. Prevention programmes have to concentrate on *high-risk behaviours* instead, that is on behaviours that expose people to infection.

Although AIDS has been a major issue of public debate nearly everywhere, it is still rather difficult to talk about AIDS and HIV transmission without evoking emotional concern. However, a majority of people worldwide—especially adolescents and youths—do not perceive themselves as being threatened by HIV transmission but feel others are, due to different sexual preferences or

certain risk-taking behaviour. *Blaming the victim* is a strategy which individuals and groups frequently choose so that they need not consider their own lifestyles.

Three modes of transmission of HIV infection have been documented so far:

- unprotected sexual intercourse (*unsafe sex*) between men and women or between men and men when one of the partners is infected with the virus;
- injection (during self-injecting drug abuse through needle-sharing of contaminated syringes and needles, through unsterilized instruments for scarification or tattooing) or by transfusion of HIV-infected blood or blood products;
- pregnancy, i.e. from an infected mother to her infant.

Sexual transmission seems to remain the major mode of HIV infection, and in this context heterosexual transmission is increasing rapidly—especially with regard to developing countries.

At least half of those infected with HIV worldwide are under the age of 25 years. As many of them are likely to have acquired their HIV infection before the age of 18 years, AIDS is also a major concern affecting the youth in every country. Adolescence, the developmental period between 10 and 19 years, and youth—as the stage between 15 and 24 years—are periods of profound physiological, psychological, and social change. They are also periods of time particularly related to behavioural experimentation in many aspects of everyday life, including sexuality and drug abuse.

Sexual intercourse between adolescents may bring about a potential risk of HIV infection. In many countries, a large number of adolescents do not protect themselves and their partners during intercourse. Sexually active young men and women often change partners before they establish a family or long-term relationships. Experimentation with illegal drugs may expose other young people to hazardous intravenous drug abuse.

In many countries, schools are a common focus of educational activities. A large number of young people throughout the world attend school or are in contact with those who do. There is a general trend towards more health education in schools, including sexual and reproductive health, family planning and HIV/AIDS prevention. However, in many countries, sexual issues—if taught at all—

are delivered in a highly constrained manner and often only with reference to biology. Very often, even family-life educators will also exclude sensitive topics of adolescent sexuality.

For young people who have left school or never had the opportunity to visit one, the situation is frequently bleak. They have only limited access to the counselling, diagnostic and treatment services of reproductive health—or, as in many countries, even this is prohibited by law, particularly with regard to youth. Thus, there is a growing need for HIV/AIDS education and outreach programmes that support adolescents and youth outside the school system.

The prevention of HIV transmission has become one of the most important elements in the work of WHO and many other organizations. As no medical cure will be available for AIDS in the near future and as no vaccine is available to prevent HIV transmission, a psychosocial approach to prevention, i.e. AIDS health promotion, seems to be of utmost importance.

LIFESTYLES CONDUCIVE TO HEALTH IN THE CONTEXT OF HEALTH PROMOTION

The WHO (1990a) has published *A Call for Action. Promoting Health in Developing Countries*, in which three principal strategies for health promotion are outlined.

- advocacy of policies;
- developing strong alliances and social support systems;
- empowering people.

Those concerned with public health have always been strong advocates of policies aimed at the improvement of health conditions. Advocacy for health is first of all *advocacy for education* in every aspect and aiming at every person regardless of age, gender, social status or religious belief. Thus, health promotion programmes are designed to collaborate closely with the formal and informal educational system.

Secondly, advocacy for health is *health-related political action* aiming at local, regional, and national politicians and political organizations. It is social lobbying for the health needs of the people.

Thirdly, advocacy for health is the struggle for *adequate resource allocation* within existing local, regional, and national budgets regarding health needs of communities. In some cases, it will be the

development of health promotion budgets, in others it will be the shifting of resources from one budget to another. We have to understand that health promotion—usually a rather weak player in the money game—has to strengthen its capacities if it is to succeed.

Fourthly, advocacy for health is *taking legal rights already existing into action*. It is surprising that in many countries, neither politicians and governments nor non-governmental organizations and social groups are aware that the improvement of living conditions and lifestyles conducive to health has been made a legal right—if only by virtue of membership of the United Nations (UN). The Declaration of Human Rights, for example, is legally binding for all member states of the UN. In the declaration and its associated laws, the protection of minorities, equality between females and males, access to education, and health care are considered to be human rights. Many countries have nationally binding laws regarding these topics. Thus, there is a good starting point for health promotion advocacy.

We will now turn to the development of strong alliances and social support systems. Health promotion, by its definition, is related to several other sectors of society. Health may be promoted everywhere because almost all social sectors contribute to health conditions. But it is also true that intersectoral collaboration is difficult to implement, since each sector follows its own sectoral objectives and policies. Nevertheless, the development of strong alliances with other social sectors than health is a priority of health promotion programmes.

Social support systems, on the other hand, refer to the circumstances in which people live. Neighbours, relatives, friends, colleagues, and the family itself are elements of the support systems. Human beings live in networks and social relations. Health promotion has to address these networks in order to reach the individual and if it reaches the individual it will have access to her/his social support systems. There is a constant interplay between the individual and the network she/he is part of. It is a formidable task for health promotion to get in touch with these systems, to enable the people to strengthen and change their relations with regard to health promotion issues, and to give support to the individual and her/his social groups in order to attain lifestyles conducive to health. We understand that building strong alliances and social support systems refers to community organizations, which is seen as a

key method of health promotion (Alinsky, 1969; Minkler, 1991).

Finally, we turn to the strategy of empowering people with attitudes, knowledge, and skills enabling them to develop lifestyles conducive to health. This seems to be the traditional area of health education, covering formal and informal education related to health. Although this is true, we feel however, that the scope of the strategy is somewhat wider.

All of us would like to find some simple things people can do to improve their health. Of course, there are some and many are issues that have been taught by health educators during the past, sometimes successfully, however rather frequently not successfully at all. As social, cultural, environmental, economic, and political conditions have become more complex these days, simple things may no longer provide adequate answers. We understand that empowerment refers to the capability of the people to share their views on health conditions with their fellow citizens and to recognize that they may have some difficulties in common. Common problems may lead to communities of people becoming enabled to solve their problems in concert. This is what empowerment means: enabling people to organize themselves as a community taking care of their living conditions and striving together for lifestyles conducive to health.

The new and broader health promotion concept takes a comprehensive social and ecological model of health and human development as its basis (Milio, 1986; WHO, 1986, 1990a). The key-term is *lifestyles conducive to health*.

The lifestyles concept draws heavily on sociological and anthropological knowledge concerning patterns of human action and interaction and their relation to health (Berger and Luckmann, 1967; Goffman, 1971; Honigman, 1973; Bennett, 1976; Hardesty, 1977; Polhemus, 1978; Bateson, 1979; Freund, 1982; Armstrong, 1983; Strunk, 1983; Crawford, 1984). A fundamental distinction is made between *collective and individual lifestyles*, which can be defined as follows:

The lifestyle of a social group characterises the totality of patterns of meaning and forms of expression which are produced by a group in the course of collective efforts to cope with the demands and contradictions of the social structures and situations common to all members of that group. The lifestyle brings together efforts related to the demands made, i.e. the external (social, political, economic and cultural) conditions and efforts related to the subjective situation and condition.

In the lifestyle is expressed under what conditions a social group acts or reacts in a particular way, i.e. the lifestyle tells us in which directions a group tends to develop its behaviour in the ongoing process of coping with the conditions in which they live. These tendencies, in the forms of common social values, norms, language forms, interaction rituals etc., provide a reservoir for individuals or subgroups which they can draw on for their personal and social identity; it makes it possible for them to give some sense and meaning to their specific situation.

The lifestyle of an individual characterises the totality of normative behavioural structures which is developed in the course of his or her life in the ongoing interaction with his or her social and natural environment. Subjective motivation and also potential action are expressed through the lifestyles and are used by the individual according to social situations. The individual's lifestyle contains variations, additions to and omissions from the collective lifestyle which are specific to that individual's personality; nevertheless the individual remains linked to this particular social group—i.e. any change in his or her lifestyle is bound by the collectively developed framework—unless, with this change, there is also a change of the social group, or it is the group which wishes to undergo such a change.

This concept of lifestyles creates a close link between the living conditions of an individual, his activities and socially formed strategies for coping with life. Characteristic for this is the linking of individual and collective lifestyles in relation to the particular socio-structural conditions in which the individual lives. Individual behaviour is understood as being largely socially determined—with the implication, among others, that to change it, social changes are necessary. Thus the message for health promotion and health education is that integrative strategies for prevention and intervention must be developed—strategies whose chief characteristic is that they link up the various social sectors and are also effective within them (Wenzel, 1983, 7f.)

The basic concept underlying the lifestyles approach is one of socialization of individuals and social groups and social interaction. Health-related behaviours of individuals and groups are viewed as reflections of certain living conditions and attempts to cope with and/or alter these conditions. Individual behaviour in a social situation is considered an outcome at a certain point in time of the life-long socialization process; since social situations change, individual behaviour is also always subject to constant change.

Using this approach, it is possible to study various aspect of health promotion and of health care, including epidemiological patterns, methods

used in providing clinical care, patient-caregiver interactions, prevention efforts, etc.

With regard to HIV transmission and AIDS, the lifestyles concept provides a frame of reference for:

- studying human behaviour and its implications for health in the ecological context of the community (for example, social epidemiology);
- identifying linkages between social, cultural, economic, environmental, and political living conditions and the development of certain individual and collective lifestyles;
- identifying the implications of individual and collective lifestyles for sexuality and other forms of behaviour such as drug use;
- identifying the value systems, normative orientations and motivational patterns of individual and collective lifestyles and their impact on sexual and other behaviours; and
- studying social support systems in the community and their impact on the development of individual and collective lifestyles conducive to health.

TARGET AREAS FOR HEALTH PROMOTION INTERVENTIONS

In order to specify appropriate approaches to and strategies for health promotion for the prevention and control of HIV and AIDS, one must analyse in detail possible target areas for preventive measures. Although various HIV transmission modes are affected by components of lifestyles, here we will primarily show how the lifestyles approach can be used to guide programmes focusing on the primary route of sexual transmission.

Sexuality can be interpreted as a specific form of bodily interaction with another person or oneself which is situated in the context of the participants' lifestyles and living conditions. Any factors impinging on individual and collective lifestyles accordingly also affect the sexual behaviours of individuals and social groups.

Sexual intercourse is embedded in a series of social situations in which persons communicate verbally and/or non-verbally their normative expectations regarding the interaction process. Usually, this communication does not include clear statements about having sexual intercourse but rather culturally—and socially—accepted messages which are understood by the persons as

expectations that their relationship will develop into a sexual one.

The intimate character of sexual relations makes it very difficult for people to communicate frankly about their sexual expectations and experiences before they have known each other for usually quite a long period of time. Individual sexual behaviour is not a matter of public debate as far as specific persons are concerned. Although many modes of sexuality are presented publicly in magazines, books, journals, videos, films, and other media, individual sexual preferences and experiences are usually not presented openly to another person at the beginning of a (sexual) relationship.

Given the above, it can be useful to distinguish focal points around which HIV/AIDS-related efforts can be developed. We will discuss three such points—sexuality and concepts of body, gender roles, and risk behaviour; it must be noted that others are possible as well (for example, sexuality and age groups, or sexuality and the concept of love).

SEXUALITY AND CONCEPTS OF BODY

Basically, health promotion aims at the improvement of body development and behaviour as well as to enhance living and working conditions at the individual and collective levels. The term *body* used here is based on anthropological and ecological concepts which assume that the *conditions of human beings* comprise physiological, psychological, social, and cultural dimensions.

In many cultures, people tend to perceive themselves and others as social beings rather than as *embodied* persons. The body seems to be a rather difficult issue in social communication except in terms of illness, disease and sports. However, as Turner (1984, p. 1) states in his book *The Body and Society*: '... human beings are embodied, just as they are enselved' and he continues:

The body is the most proximate and immediate feature of my social self, a necessary feature of my social location and of my personal enselvement and at the same time an aspect of my personal alienation in the natural environment (Turner, 1984, p. 8)

The body is the bearer of the human being and at the same time the expression of his/her existential—i.e. economic, political, social, cultural and environmental—situation. Individual

and social biography are represented in the body, as are the social and cultural circumstances in which it developed; moreover, economic and ecological living conditions also find their expression in the human body. Therefore, body awareness, bodily experiences, and bodily expressions are not only subject to individual choices of one lifestyle over another; they are primarily structured by social communication and interaction, both of which are dependent upon the symbolic structure of the social system, i.e. the value system, normative expectations, and symbolic categories such as health, wealth, happiness, satisfaction, power, etc. Relationships between the individual and collective, between personal and social development, between economic and ecological processes are both directly sensed and expressed by the body.

In introducing the concept of the body as a key element in health promotion, we are referring to the materialistic basis of both health and disease. All measures taken in this respect have an impact on body awareness, bodily experiences, and bodily expressions. They interfere with bodily communication and the interaction of individuals and groups.

There is one aspect of the body which has become more and more relevant for health promotion: the presentation of the self as a bearer of a specifically-styled body. Individual and collective strategies for the development of successful images of the body are pursued in a variety of social and cultural settings. As Turner (1984, p. 111) states: 'successful images require successful bodies, which have been trained, disciplined and orchestrated to enhance our personal value'. The symbolic power of fashion and the associated trained, styled, and altered body are obvious. Practices such as scarification, tattooing, and circumcision are clear examples of this. Turner further adds (1984, p. 112): 'We jog, slim and sleep not for their intrinsic enjoyment but to improve our chances at sex, work and longevity.' The body is thus used as a tool to enhance individual and social attractiveness. It is not viewed primarily in terms of health but in terms of social and thus sexual relations too. Health may be a prerequisite, but it is certainly not the objective of such body management.

Given the above, it can be seen that *health* may play a minor role in people's body-related thoughts and actions. The WHO definition of health focuses on physical, mental, and social well-being as indicators of health. In many

cultures, however, well-being seems to be related to fun, pleasure, relaxation, happiness, productivity, reproduction, etc., but not necessarily to *health per se*. One implication of this may be utilized regarding HIV/AIDS-related health promotion in the context of (sexual) relationships: *safe sex* promotion might focus on the message that the person who takes precautions is a more attractive potential partner.

SEXUALITY, REPRODUCTION AND GENDER ROLES

Gender roles and gender relationships are always subject to change. This fact is of particular relevance with regard to ways in which people can protect themselves and others against HIV transmission. For example, in considering condom use, the differences between contraceptive behaviour and protective behaviour must be analysed in order to specify how health promotion can best approach this topic.

Sexual behaviour provides a means of satisfying desire and gaining pleasure and subsequent relaxation, either alone or with another person. However, it may also give rise to problems, such as preventing unwanted pregnancy.

As far as contraception is concerned, communication about its behavioural implications takes place—if at all—before people decide to have sexual relations. In particular, contraception is interpreted by men as a female task; women must take care not to get pregnant. Contraceptive methods such as the pill and diaphragm are handled by women. There is one important implication of contraception: it is frequently interpreted as a medical approach to preventing unwanted pregnancy and not so much as a social and psychological means of freeing sexual intercourse from the threat of unwanted pregnancy. Contraceptive behaviour is aimed at avoiding reproduction, not at preventing certain diseases.

With the advent of HIV transmission, the situation has become completely different. First of all, each act of sexual intercourse carries the risk of contracting or transmitting the virus as long as no one can be certain whether she/he is already infected. Therefore, the prevention of transmission is essential in order to protect oneself and the other person from infection. In this respect, the prevention of HIV transmission is a complementary act: I not only protect myself against a certain hazard but also protect another from

getting infected in case I have already contracted the virus. The responsibility for this preventive measure thus lies not only with the individual, but also with his/her partner and his/her future partners. HIV prevention consequently has both individual and collective aspects (Bateson and Goldsby, 1989, p. 101).

In this context, there is no other decision to be taken than to use condoms when sexual intercourse takes place. Condom use is exclusively a male task, i.e. women cannot protect themselves against HIV infection except by asking men to use condoms or by choosing non-penetrative forms of sexual contact. In contrast to unwanted pregnancy or sexually-transmitted diseases, HIV infection cannot be treated medically, i.e. if a person has contracted the virus, she/he often may have to cope with the subsequent disease. The threat of HIV transmission thus has consequences for female/male relations and the balance of power between the sexes. Since the transmission of HIV infection can only be reduced via condom use, women cannot protect themselves against it without the collaboration of men. They must depend on them for protective behaviour. As far as contraception is concerned, women have the possibility of controlling their reproductive systems themselves in one way or another. Regarding HIV transmission, their bodies are placed somewhat outside their control. This shift in the balance of power has effects on female self-esteem and, probably, on women's behavioural intentions regarding sexuality and sexual behaviours.

While the modes of HIV transmission seem to be rather clear and the need for preventive measures cannot be neglected, many people seem to have difficulties in adjusting their behaviours accordingly.

Condom use may be considered in some cultures as a behaviour which does not permit direct bodily interaction; the artificial product *condom* is viewed as being contrary to the nature of sexuality. Condoms may be considered socially as representing a concrete request for sexual intercourse, i.e. those who have condoms available are suspected of wanting to have sexual intercourse. The condom becomes a symbol of sexual desire; it makes the private desire public. Luker (1978) found a similar interpretation among women concerning the use of diaphragms. Finally, condom use may be considered as an interference in the behavioural process of sexuality, a disturbance of the intimacy of the sexual

process and an interruption in the process of satisfying lust and gaining pleasure.

For all these reasons, the content of HIV/AIDS-related health promotion should again be considered very carefully. Campaigns would focus on changing social norms so that condom use comes to be viewed as a common, *normal* and desirable behaviour. The fact that precautionary measures can remove a cause for worry (that is HIV transmission), thus enhancing feelings of trust and intimacy, could be an advantageous message.

RISK BEHAVIOUR

Individuals and groups develop behavioural patterns and strategies which help them to cope with the requirements and contradictions inherent in their ecological and economic living conditions. These not only involve health-promotive behaviours; people also practice health-hazardous behaviours for different reasons. Within the framework of the lifestyles approach, the concept of risk behaviour has been used to reflect upon those living conditions and social situations in which people might carry out certain behaviours for a specific period of time which can be considered by others as health-hazardous; however, the individuals involved may not feel the hazards are important as long as the positive effects of the behaviours are qualified as superior, both individually and collectively. This is certainly true with regard to specific sexual behaviours in relation to HIV transmission and AIDS. It is, therefore, important to study the concept of risk behaviour and its implications for health promotion. Three aspects need to be discussed further.

(1) The function of risk behaviour is to help individuals and groups manage the difficulties and problems of everyday life. It would be a misconception to view risk behaviours *per se* as deviant behaviours. They are well-accepted by the social groups who carry them out irrespective of what other social groups think of them. Several risk behaviours are socially more or less accepted such as drinking alcohol, smoking cigarettes, sunbathing, taking pills, having sex with multiple partners, driving fast, etc., while others are viewed as unacceptable by society-at-large, such as *train-surfing* (a practice in Latin American and European countries where youths ride atop highspeed trains standing upright). Some are presented in

the context of sports such as freestyle mountain climbing (in the USA the slogan is: *if life gets boring, risk it*), deep-sea diving, high-speed skiing, high-speed motorboat driving, bull-fighting etc.; they communicate the message that those who carry out these sports are somewhat like heroes (at least for one day).

(2) The outcomes of risk behaviours are mainly relaxation, pleasure, fun, i.e. well-being for a short period of time. Risk behaviours involve only a short-term time perspective. They are always oriented towards a specific social situation and are characterized by a desire to achieve well-being as quickly as possible. In most cases, therefore, risk behaviours are related to leisure because in this temporal context people have more individual and collective opportunities to decide upon what they want to do. This particular social sector has been developed in the European and North American regions according to commercial and industrialized patterns. Numerous facilities offer services which meet peoples' desire to achieve relaxation, pleasure, and fun. From a sociological point of view, one can argue that there is an industry offering facilities for risk behaviours—and it meets people's needs to get away from everyday life for a certain amount of time. This short-term time aspect of risk behaviours is an important factor with regard to health promotion. Health-related behaviours rather frequently are time-consuming and also bear some amount of uncertainty regarding their results, while risk behaviours related to alternatives offering immediate well-being regardless of their potentially health-hazardous effects. For example, after a day full of stress, an individual may decide to unwind by practising meditation, taking a nap or doing relaxation exercises, all of which can be beneficial health-wise. However, the alternative of visiting a bar to have a drink is often more attractive, though it might be damaging to health depending on how much the person drinks. *Life in the fast lane* (Franzkowiak, 1987), or living in *computime* (Risfin, 1989) does not seem to allow for long-term considerations concerning well-being. Risk behaviours thus tend to become an integral part of every lifestyle. The question is whether or not we will be able to reduce the potentially health-hazardous effects of these behaviours.

(3) Risk behaviours are perceived as individual and/or collective attempts to gain control over certain situations in terms of well-being. The functionality underlying risk behaviours does not

TARGET AUDIENCES

In AIDS health promotion for youth, primary audiences are those young people who will receive immediate and direct education, skills training, and social support. Secondary audiences consist of people who influence the primary target audiences or the community as a whole. Among them may be adolescent peers, but mostly key adults from the community. Those community groups are defined as secondary audiences whose support and involvement is desirable for programme implementation. It is mandatory to also target local people who have been opposing AIDS health promotion efforts or are likely to produce obstacles to the programme in order to win their support or, at least, *neutralize* their negative influence.

Primary target audiences

Young people are a diverse and mixed population. In a community or area, programme developers are likely to find a wide variety of ethnic, cultural, social class, and religious backgrounds. There will also be important age and gender divisions or differences in education and health knowledge. Experience of adolescents in isolated rural communities is normally different from those in the heart of cities or from those *on the streets* in metropolitan areas. Every young person's need for accurate information and for positive responses to their needs, however, is just the same everywhere.

The selection of primary target audiences is to be based on sound epidemiological evidence, comprehensive knowledge about common physiological, psychosocial, and cultural steps in the sexual and personal development of adolescents, and on results of an initial community assessment. Given this, highest priority should be given to those young people who practice high-risk behaviours such as:

- unprotected sexual intercourse;
- exchanging sex for money and drugs;
- drug abuse, particularly intravenous drug abuse;
- abuse of alcohol or prescribed drugs, and use of illicit drugs;
- skin-piercing other than intravenous drug abuse (e.g. tattooing).

High priority should then be given to adolescents and youth:

- who have not previously received HIV/AIDS education, and therefore have no or inaccurate knowledge, inadequate attitudes as well as insufficient behavioural skills;
- who may have already received some kind of HIV/AIDS education, but upon examination still show inaccurate knowledge, inadequate attitudes or insufficient protective behaviours.

In addition to these high priority youth, AIDS health promotion should be addressed to

- all young people who are developing sexual relationships;
- all young people who start to experiment with drug abuse or have friends who do so.

When and how adolescents start sexual intercourse or experiment with drug abuse will vary between cultures, countries, and communities, also depending on religious and legal norms and values. Even within one culture, health promoters are likely to find differences in the onset of risky practices and the practices themselves. Young people in metropolitan regions very often start earlier with sexual behaviours or drug abuse than boys and girls in rural areas. One should also prepare for large differences between male and female youth or different ethnic and social class sub-groups regarding experience related to sexual behaviour and drug abuse.

Adolescents and youth at greatest risk of infection may be identified through available epidemiological data related to the prevalence of high-risk sexual and drug-abusing behaviours in the region or community. If such data are not available, one can refer to information gathered from health and social workers or other community members about the *vulnerability* of these young people to HIV transmission because of high-risk behaviour patterns that they usually perform (but which have not yet been identified by epidemiological surveillance—as in the case of *street kids* or drug abusers being also sex workers, etc.).

Secondary target audiences

In selecting these audiences, highest priority should be given to peers and adults influencing the sexual behaviour of the young population or making actual decisions about issues of sexuality (or drug abuse) in the community. An initial assessment provides programme developers with sufficient information to identify decision-makers

and opinion-leaders being relevant to the community and its young people.

On this background, secondary audiences may include:

- youth leaders from schools, youth organizations or informal gatherings such as *street sub-cultures*;
- parents and teachers;
- religious leaders, clergymen, and church staff;
- political leaders;
- pop stars and other celebrities, such as athletes;
- medical doctors, community nurses, and health staff;
- media representatives;
- editors of youth magazines;
- social workers, youth workers, and other educators;
- members of the police force and correctional services.

HIV-infected youth

In many parts of the world, it may be assumed that some of the targeted adolescents and youth or some of those who participate in a programme may already be infected with HIV. Many young people may suspect that they are infected and where antibody testing is available and taken, some may be sure that they are. Young people who are infected with HIV face many problems related to partnership, sexuality, work, and social relations. The existence of these young people must in no case be denied; neither must health promoters only be concerned about them with regard to preventing them from transmitting HIV to others. Their well-being is important and should play an integral part in programme development and implementation.

Information, training, and social support for those adolescents and youth living with AIDS, HIV-infection, or receiving the results of HIV-antibody testing cannot be put back in AIDS health promotion. These youth need to be helped to understand their medical, emotional, and social situation. They also need education to avoid risky behaviours, and to help them coping with possible physical or social handicaps and discrimination.

HIV-infected adolescents and youth need support in their life settings, and in making life choices. They not only have to deal with eventual illness but also to cope with years of life during which they feel physically well. The same *safe sex* practices that protect uninfected youth will protect HIV-infected young people from further exposure to HIV or other STDs that may place stress on their immune systems.

PROGRAMME DEVELOPMENT

The development of AIDS health promotion for youth programmes should consist of ten steps as shown in Figure 2.

Adolescents and youth at greatest risk of infection—as a result of behaviours they may practice, and the known or presumed prevalence of HIV in the region they live in—should receive immediate attention when developing a programme. In some countries, HIV/AIDS prevention programmes for young people put special emphasis on the development of self-esteem, communication, and decision-making skills, and put an emphasis on peer education aiming at *behavioural immunization* against risk-taking habits. Reflecting the needs of homeless adolescents and street kids,

1. Collecting necessary information through an *initial assessment* in the community (assessing the youth situation in general, the HIV/AIDS situation among and for youth in particular, and the availability of preventive community resources)
2. Setting up programme goals and objectives
3. Deciding upon main contents and messages of the programme
4. Selecting one or more target audience(s) of the programme
5. Securing community acceptance, networking for community involvement and ensuring young people's participation in all stages of the programme (preparing against sources of resistance or potential opponents to the programme, promoting public discussion about HIV/AIDS and young people, seeking local allies and political support, establishing advisory boards or local 'taskforces')
6. Looking for effective ways to reach the target audiences (that is, identifying effective channels of communication) and developing practical prevention strategies
7. Pretesting or piloting interventions
8. Planning or monitoring, evaluation and reassessment of the programme
9. Establishing a programme timetable (schedule) and budget
10. Implementing the programme in the community

Fig. 2: Steps of programme development in AIDS health promotion for youth.

unconditional *survival support* is often included, like housing, nutrition, medical care, and education.

Effective behaviour change will take a long time. Programme planners should plan for a repetition and extension of programme activities over a number of contacts, which can last for months or even years. Information sessions and behavioural trainings for the target audiences have to be presented repeatedly and in different social contexts over a longer period of time. Through this, it is to be ensured that preventive messages and related behavioural changes can be picked up at the time members of the audiences are ready for it and also in settings where they feel secure and comfortable enough to get involved.

Information sessions, skills training and rehearsal, and support activities can and should be simple, frank and direct. It is neither necessary nor appropriate to concentrate efforts only on teaching biomedical information about HIV/AIDS. Instead, the focus should be upon (a) simple, concise information and practical training of how to avoid an infection of oneself and others, and (b) the implementation of social support and community resources.

In preparing for programme development, AIDS health promotion professionals should consider the practical recommendations indicated in Figure 3.

It may often be important, even necessary, to seek and develop culture-specific methods and strategies to challenge apparent *cultural barriers* to effective communication about HIV/AIDS, adolescent sexuality, and injecting drug abuse. The help and collaboration of community leaders, youth leaders or community and youth workers from the non-medical professions should be welcomed by programme developers.

- ◆ Educate about basics first (presenting the basics about communicable diseases and drug abuse before specifically getting into HIV/AIDS; educating about adolescent sexuality, and adolescent development)
- ◆ Present understandable messages (presenting messages, materials, and group exercises simply, so that anyone involved directly, such as adolescents and youth, or indirectly, like parents, community officials, or health professionals, can understand and participate)
- ◆ Be specific, explicit and non-moralistic (informing comprehensively about sexual activities, how to get and how to correctly use condoms, intravenous drug abuse, the situation and life-styles of sexual minorities, and the overall life conditions of the target audiences)
- ◆ Be prepared for gender, ethnic and social class differences (being aware of strong gender, ethnic and social class divisions in adolescent development, sexuality and risk-taking behaviors; consequently, designing the programme so that there is space and time for gender- or ethno-specific information and training, e.g., addressing and training girls and boys separately, for a certain period of time regarding specific issues)
- ◆ Respect parent and community values (being sensitive to culturally-framed or community-based ethical and moral preconceptions about adolescent sexuality and HIV/AIDS; if necessary, getting parental, other educators' and guardians' consent before getting involved in frank and explicit preventive information, discussions and training with young people)

Fig. 3: Methodological guidelines for AIDS health promotion for youth programmes.

COMMUNICATION CHANNELS AND INTERVENTION APPROACHES

It is necessary to create and present understandable messages concerning HIV/AIDS prevention for sexually active and/or drug abusing young people in order to influence their knowledge, values and behaviours. However, as the history of health education against communicable diseases and decades of only slightly effective drug abuse prevention have shown, this is not enough. It is the choice of the right medium that bears an equal significance for preventive success and the right message (Hornik and Romer, 1990). Therefore, all messages should be delivered in a way that:

- actually reaches the adolescents and youth in question;
- is sensitive to the needs and lifestyles of the defined target audiences;
- uses or contributes to improving social support and changing relevant community resources to a maximum.

In AIDS health promotion, a key term is *channels of communication*. To be or become effective, channels of communication must be:

- *credible and sensitive* (having credibility for the target audiences, being able to respond to their needs and concerns, and being sensitive to cultural, ethnic, social, and gender differences);
- *understandable* (being able to transmit the necessary information according to the young males' and females' educational and literacy level, language, attention span, lifestyles, gender role, ethnic or social class divisions and still be in accordance with the programme content);
- *available and frequent* (being able to actually

- reach the target audience and to reach the young people frequently and repeatedly);
- involving* (having the capacity to capture young people's attention and involvement);
- stimulating* (being able to stimulate discussion or group activities by activating informal social networks);
- participatory* (supporting the real participation of young people as well as other target audiences and the community in the programme);
- feasible* (being operationally feasible for programme workers);
- cost-effective* (being cost-effective over time including the ability to be sustained even after programme developers' input has finished).

There are two main channels to deliver preventive messages:

- personal communication;
- mass communication.

Personal communication

Here, messages are delivered to individuals or small groups of people through face-to-face interaction and communication. Intervention methods may include classroom teaching, group instruction, behavioural training workshops, individual or group counselling, group discussions (*focus groups*), and community outreach.

Rather than mass communication strategies, strategies of personal communication have proven to be effective with high-risk behaviour audiences. A good example is the work of outreach educators. Outreach workers walk the streets and places where drug abusers, street kids and other hard-to-reach youth live. They distribute condoms and convey explicit messages and skills which otherwise could hardly be communicated as they would not be permitted in public or on mass communication channels.

Mass communication

Here, a general audience is addressed that is and may well stay individually unknown to communicators. Common approaches include the use of print media (such as newspapers, magazines, comic strips, and information sheets) or billboards and posters, broadcasting of radio and television spots, public showing of films and videotapes, public awareness campaigns (e.g. for condom promotion), staged community events (*AIDS action days or weeks*, street theatre and drama, music festivals, and use of folk media), and

public appearances of teen idols and respected youth spokespersons.

Mass communication may be appropriate for reaching and influencing larger youth audiences. They can be addressed on the streets and in market-places, at worksites, at music festivals or folk media events, in discotheques, or as an audience to popular youth radio and television broadcasts. AIDS health promotion professionals may reach out to larger groups of organized youth like, for instance, males in the military system or adolescents and youth in local and national youth organizations.

One will usually achieve greater exposure of preventive messages through mass communication. However, it is not always the best choice. Mass communication channels may not be appropriate if a programme aims at young people who:

- are at high behavioural risk for HIV infection (e.g. temporary or dependent injecting drug abusers, street kids practicing *sex for survival*, adolescent males having unprotected sex with men, etc.);
- can only be accessed through highly explicit messages about behaviours that are socially wholly or only partly acceptable (such as explicit safety rules concerning injecting drug abuse);
- are mobile;
- may be resilient to authority or established channels of information giving.

Personal or mass communication?

In many cases, a combination of mass and personal communication strategies is recommended. One may start in a step-by-step fashion. At first, broadcasting, posters, billboards, and community events are used to inform the target audience about HIV/AIDS threats and prevention. After having enhanced young people's awareness, health promoters may switch to personal channels such as outreach, street, and youth work, or counselling. By follow-up personal communication the effectiveness of mass communication on the behaviour of the young people can and will be increased. Condom promotion campaigns for smaller, high-risk behaviour target audiences have been carried out successfully in many countries by using this step-by-step approach.

Personal communication is often more expensive, shows a limited capacity to reach larger audiences, and may require a significant amount of programme time to do so. It can be more cost-

effective, however, in changing attitudes and intentions of young people, especially of those who are hard to reach. Mass communication strategies will reach larger audiences, but may not be sensitive, credible, or explicit enough for groups of young people who engage in high-risk behaviours. The mass-plus-personal strategy is appropriate for many cases, but it should not be considered a *simple blueprint* for all programmes and target audiences.

Figure 4 gathers a whole range of intervention approaches that may be regarded as effective in AIDS health promotion for youth.

IMPROVING COMMUNITY RESOURCES AND ESTABLISHING SUPPORTIVE ENVIRONMENTS

Reorienting available health services

If HIV/AIDS-related services or treatment facilities are available in a community, they may be used as important channels to reach out to the target audiences—thus, also reorienting their service profile. Clinics, ambulatories, mobile health services and their personnel are widely considered credible and effective for obtaining health information and treatment. Young people attending such services are likely to be responsive to information and education offers.

Clinics, hospitals, and their staff can also reach out to high risk behaviour groups through the provision of HIV-antibody testing. Testing must, without exception, be voluntary, non-compulsory, and confidential. Otherwise the audience will not trust the credibility of this offer and of the whole programme and will never accept it. It is mandatory to combine testing with pre- and post-test assistance and counselling. HIV/AIDS information and preventive behaviour advice must be given to all young people who participate, regardless of their tested antibody status.

Programme developers must prepare for the special situation of young clients with positive test results. As they are carrying an HIV infection with the prospect of contracting AIDS sooner or later, they should be offered (or referred to) intensive medical and psychological counselling. These adolescents and youth need long-term assistance and support; on the other hand, they must be educated in order to prevent them from spreading the infection to others.

Particularly when working with hard-to-reach groups, AIDS health promoters may often find it necessary to integrate HIV education and training into a comprehensive assistance programme. Audiences like urban homeless children and adolescents, mobile urban and rural youth, or male and female adolescents engaging in prostitution for money, food or comfort have needs and

Personal communication approaches

- ◆ HIV/AIDS education and counselling (in some places also condom distribution) in and out of schools, in discotheques and other informal youth settings
- ◆ Demonstration, role-playing and training workshops for adolescents and youth in and out of schools (including proper condom use and the rehearsing of protective skills in order to resist negative peer pressure)
- ◆ Peer education and protective skills training in schools, in out-of-school settings, with and for drug abusers in their own *scenes*, for adolescent prostitutes, with and for young men having sex with men, etc.
- ◆ Community outreach aiming at these target audiences
- ◆ Involvement of local youth organizations and the whole community in peer education, community action, and solidarity for young and older people with HIV/AIDS
- ◆ Telephone helplines and information hotlines

Mass communication approaches

- ◆ Development and distribution of printed materials, photomagazines, and comic books for adolescents and youth in schools, out of schools, in specific target audiences, with different levels of literacy, regarding different levels of explicit language to be used, etc.
- ◆ Radio and television broadcasts
- ◆ Billboards and poster displays in and out of schools, in public places, informal gathering areas, hospitals and doctors' offices, police stations and correctional institutions, etc.
- ◆ Public awareness campaigns and condom promotion in the whole community and/or for specific target audiences in their life settings
- ◆ Public screening and mobile projection of educational films and videotapes for adolescents, youth, parents and other concerned adults
- ◆ Community events, use of folk media, and HIV/AIDS education through drama or plays

Fig. 4: Effective communication channels and intervention approaches in AIDS health promotion for youth.

concerns that go far beyond accurate and explicit HIV/AIDS education. To improve chances of getting close to these young people, it may often be necessary to react to their basic needs first. These will normally include shelter, nutrition and clothing, medical care and emergency treatment, education, job and social skills training.

Networking for supportive environments

Preparing for possible resistance and resilience to AIDS health promotion for youth is of extreme importance. Keys to reducing community resistance are involvement and positive communication. To safeguard against obstacles, community leaders, such as political and religious leaders or legal representatives, should be involved in programme development and programme review from the start. It is also essential to include youth leaders or target youth into these consultations to help community leaders recognising the needs that the programme has to address (and, if need be, to help them understand why some explicit messages or educational methods may be employed).

Figure 5 suggests concrete ways to overcome resistance to an AIDS health promotion for youth programme. They were developed and field-tested in the context of condom promotion.

On the local level, networking is an essential instrument for gaining active allies and securing community involvement. Its aim is to establish a coherent network of relevant people, groups and organizations ensuring that all programme activities are coordinated and integrated. Networking depends on strong coordination which should remain in the hands of programme planners and developers. Networking is an effective tool for disseminating information and methodology, spreading responsibility, creating commitment, and gathering expertise and resources.

When building up a network of programme supporters, the following groups and people may be approached and asked for their collaboration:

- youth leaders, representatives from youth organizations and associations, and other representatives of non-government organizations;
- parents and parent organizations;
- teachers and representatives of school and vocational education authorities;
- members of local press, radio, and television;
- editors of youth magazines;
- youth workers, social workers, and their local administration;
- children's youth and women's rights organizations, self-help groups and counselling agencies;
- medical doctors, community nurses, and other professionals from local health care institutions and counselling agencies;
- religious and church leaders;
- political leaders from the community or region;
- police officers and (if targeted) detention or army officers;
- owners of coffeebars, and discotheques and clubs.

There are many advantages regarding the involvement of community members, such as parents, teachers, and doctors, in the programme. This involvement gives more credibility to all programme activities. It will increase the likelihood of AIDS health promotion becoming widely accepted and also encourage the selection of programme workers being acceptable to the community.

MONITORING AND EVALUATION

Monitoring

Through monitoring, information is collected and analysed about proper programme implementation. This involves regular checking to see whether programme activities are being carried out as planned and to control for probable

- ◆ Gain political support from the highest possible sources
- ◆ Win local allies for the programme, especially among the press and media and with community spokespersons
- ◆ Meet with potential opponents early to hear their views
- ◆ Inform opponents fully about the programme's goals and messages, its target audiences, the selected educational strategies and materials
- ◆ Emphasize condom use and its importance for disease prevention especially to religious authorities and parents
- ◆ Avoid offensive jargon or use of explicit messages if this is offensive
- ◆ Be innovative and try to find out ways to by-pass restrictive regulations concerning public discussion of young people's sexuality or drug abuse

Fig. 5: How to deal actively with potential community resistance to AIDS health promotion for youth programmes.

problems, sources of resistance, or lack of human and other resources.

Monitoring is an integral part of implementation; it is incorporated from the start of the programme. Preferably, already existing information and reporting resources in the community are utilized such as the local press and community administration. Monitoring must be carried out at frequent intervals (for instance, once a month or every 6 weeks). It is recommended to apply simple information-gathering techniques that are not costly and provide a rapid feedback.

Programme monitoring in AIDS health promotion for youth keeps track of the following general indicators:

- *achievements* (e.g. what does the programme achieve during set intervals of time? What have been setbacks or failures? Is all planned information and training available to target audiences at the right time?);
- *utilization* (e.g. how are community and human resources utilized? How are information and training offers, printed materials, support programmes, etc. used by the target audiences?);
- *supplies* (e.g. how many supplies and how much equipment is needed over time? Do members of target audiences have access to condoms or clean syringes?);
- *staff* (e.g. who works for the programme? Are there changes regarding programme staff and other people involved?);
- *audiences* (e.g. how do target audiences and the community react to the programme? What are the main sources of information and training? Do they have proper access to programme activities and services?).

Common monitoring techniques (that can also be applied for evaluation purposes) include:

- *surveys* (periodic questionnaire surveys with members of the target audiences, youth leaders, peers, parents and family members, teachers, etc.);
- *interviews and discussions* (periodic discussions and interviews with all of the above as well as community leaders);
- *work reports* (periodic checks from programme workers and other personnel);
- *service checks* (periodic checks with service outlets and other institutions involved in programme implementation);
- *media coverage* (periodic monitoring of mass media such as local and regional press, radio and television reports).

Evaluation

Evaluation means to collect and analyse information about programme effectiveness and impact as a whole or with regard to some of its elements and stages. Evaluation is crucial in the process of pretesting materials and piloting interventions, and it also includes a later reassessment of programme achievements. Evaluation provides data about how information, education, training, and social support have influenced the HIV/AIDS-related knowledge, attitudes, beliefs, practices and skills of the target audiences. Wherever possible, available epidemiological indicators, such as changes in STD and/or HIV incidence during the course of an intervention, should be integrated into the process of impact evaluation. Evaluation is not an optional extra: it is and should always be an integral component of the preventive process.

In AIDS health promotion for youth the indicators given in Figure 6 are relevant (WHO, 1990b).

- ◆ *Access* (i.e., did the target audiences have access to the chosen channels of communication? Did education and training meet their needs and priorities?)
- ◆ *Exposure* (i.e., how many adolescents and youth in and out of the selected target audiences were reached by the programme messages? How often were they reached? How many young people could be reached by information sessions, peer education, and behavioural skills training?)
- ◆ *Comprehension* (i.e., how clearly were the messages understood by members of the target audiences? Which of the chosen methods and communication channels contributed to comprehension, which ones did not?)
- ◆ *Condom use* (i.e., how many condoms were distributed at which programme stages? To whom were they distributed, and how often? Did the reported frequency of condom use by adolescents and youth change over programme time?)
- ◆ *Mobilization of community resources* (i.e., which agencies and persons from the community could be mobilized to get involved with the programme? Which community resources were available, which were not and why not?)
- ◆ *Social support* (i.e., could a social support system be developed related to young people with high-risk behaviours or to HIV-infected adolescents and youth? What were promoting factors for this, where and who were barriers?)

Fig. 6: Evaluation indicators for AIDS health promotion for youth programmes.

ASSESSMENT

Assessment means to take a second look at the impact, outcome, and efficiency of an AIDS health promotion for youth programme. After finishing the programme and its evaluation, it is useful to reflect on results and the experience gathered during its conduct.

Planned reassessment permits a reorientation of programme implementation or future programmes. In most countries, the HIV/AIDS situation is changing rapidly. National AIDS plans and programmes for young people must be flexible enough to respond to new problems as they arise and to pinpoint the shortcomings of previous programmes.

Address for correspondence:

Professor Dr Peter Franzkowiak
Hochschule Rheinland-Pfalz
Postfach 12 55
55075 Koblenz
Germany

REFERENCES

- Singleton, P., Horsley, C., Warwick, I. and Wilton, T. (1990) *AIDS—Working with Young People*. AVERT, Horsham, West Sussex.
- Wills, G. A. (1959) *Reveille for Radicals*. Vintage Books, New York.
- Armstrong, D. (1983) *Political Anatomy of the Body*. Cambridge University Press, London.
- Jameson, G. (1979) *Mind and Nature. A Necessary Unity*. Dutton, New York.
- Jameson, M. C. and Goldsby, R. (1989) *Thinking AIDS. The Social Response to the Biological Threat*. Addison-Wesley, Reading, MA.
- Strenn, J. W. (1976) *The Ecological Transition. Cultural Anthropology and Human Adaptation*. Pergamon Press, New York.
- Merger, P. L. and Luckmann, T. (1967) *The Social Construction of Reality. A Treatise in the Sociology of Knowledge*. Penguin, Harmondsworth.
- Rawford, R. (1984) A cultural account of 'health': control, release, and the social body. In McKinlay, J. B. (ed.) *Issues in the Political Economy of Health Care*. Tavistock, New York, pp. 60–103.
- Robben, R. (1991) Health challenges for the year 2000: health promotion and AIDS. *Health Education Quarterly*, 18, 29–37.
- Franzkowiak, P. (1987) Risk-taking and adolescent development. *Health Promotion International*, 2, 51–61.
- Franzkowiak, P. (1990) Adolescent development and its implications for AIDS prevention. *AIDS Health Promotion Exchange* (Newsletter of the Global Programme on AIDS of the World Health Organization, Geneva), 1, 1–2.
- Franzkowiak, P. and Wenzel, E. (1991) Guide on health promotion for the prevention and control of HIV/AIDS among out-of-school youth. Geneva (WHO/GPA), Draft, 1991.
- Freund, P. (1982) *The Civilized Body. Social Domination, Control, and Health*. Temple University Press, Philadelphia.
- Goffman, E. (1971) *Relations in Public. Microstudies of the Public Order*. Basic Books, New York.
- Hardesty, D. L. (1977) *Ecological Anthropology*. Wiley, New York.
- Honigman, J. H. (ed.) (1973) *Handbook of Social and Cultural Anthropology*. Rand McNally, Chicago.
- Hornik, R. and Romer, D. (1990) Background paper for WHO Technical Working Group meeting on accessing and communicating with youth, Geneva (WHO/GPA), 29–31 August 1990.
- Luker, K. (1978) *Taking Chances. Abortion and the Decision not to Contracept*. University of California Press, Berkeley.
- Mann, J., Tarantola, D. and Netter, T. (eds) (1992) *AIDS in the World*. Harvard University Press, Cambridge, MA.
- Milio, N. (1986) *Promoting Health Through Public Policy*. 2nd printing. Canadian Public Health Association, Ottawa.
- Minkler, M. (1991) Improving health through community organization. In Glanz, K., Lewis, F. M. and Rimer, B. K. (eds) *Health Behavior and Health Education. Theory, Research and Practice*. Jossey-Bass, San Francisco, pp. 257–287.
- Nutbeam, D. and Blakey, V. (1990) The concept of health promotion and AIDS prevention. A comprehensive and integrated basis for action in the 1990s. *Health Promotion International*, 5, 233–242.
- Polhemus, T. (ed.) (1978) *Social Aspects of the Human Body*. Penguin, Harmondsworth.
- Rifkin, J. (1989) *Time Wars*. Simon & Schuster, New York.
- Smallman-Raynor, M., Cliff, A. and Haggett, P. (1992) *London International Atlas of AIDS*. Blackwell, Oxford.
- Strunk, D. (1983) *Political Dimensions of the Body*. Cambridge University Press, London.
- Turner, B. S. (1984) *The Body and Society. Explorations in Social Theory*. Basil Blackwell, Oxford.
- Wenzel, E. (1983) Lifestyles and living conditions and their impact on health. *Scottish Health Education Group, European Monographs in Health Education Research*. Vol. 5, SHEG, Edinburgh, pp. 1–18.
- World Health Organization (1986) Ottawa Charter for health promotion. Ottawa, 21 November 1986.
- World Health Organization (1990a) *A Call for Action. Health Promotion in Developing Countries*. WHO, Geneva.
- World Health Organization (1990b) School health education to prevent AIDS and sexually transmitted diseases: a guide to teaching and curriculum development. Geneva (WHO/GPA), Draft, 1990.

13

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

The current global situation of the HIV/AIDS pandemic

As of 30 June 1996, 1 393 649 cumulative AIDS cases in adults and children have been reported to WHO since the onset of the pandemic. This represents a 19% increase from the 1 169 811 cases reported to 1 July 1995.

The accompanying table provides the number of reported AIDS cases to date, by continent.

Fig. 1 presents the global distribution of reported and estimated AIDS cases as of mid-1996. Allowing for under-diagnosis, incomplete reporting and reporting delay, and based on the available data on HIV infections around the world, it is estimated that over 7.7 million AIDS cases in adults and children have occurred worldwide since the pandemic began.

La pandémie mondiale de VIH/SIDA: situation actuelle

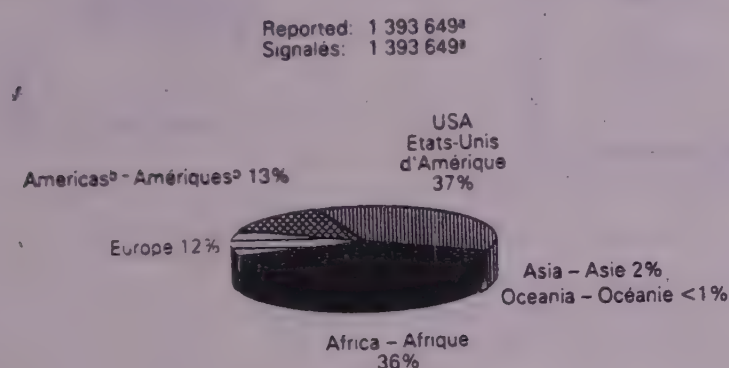
Au 30 juin 1996, un total de 1 393 649 cas de SIDA chez les adultes et les enfants avaient été signalés à l'OMS depuis le début de la pandémie. Cela représente une augmentation de 19% sur les 1 169 811 cas signalés au 1^{er} juillet 1995.

Le tableau ci-contre donne le nombre de cas signalés jusqu'ici, par continent.

La Fig. 1 indique la répartition au niveau mondial du nombre de cas signalés et du nombre estimé de cas de SIDA au milieu de l'année 1996. Compte tenu du sous-diagnostic, ainsi que des lacunes et des retards dans la déclaration des cas, on estime, en s'appuyant sur les données disponibles concernant les infections à VIH dans le monde, qu'environ 7,7 millions de cas de SIDA se sont produits chez les adultes et les enfants à l'échelon mondial depuis le début de la pandémie.

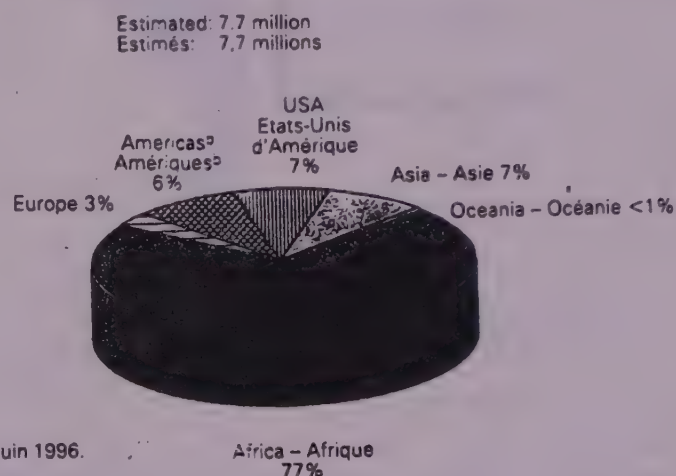
Fig. 1 Total number of AIDS cases in adults and children from late 1970s/early 1980s until mid-1996

Fig. 1 Nombre total de cas de SIDA chez les adultes et les enfants depuis la fin des années 70/début des années 80 jusqu'à la mi-1996



^a AIDS cases reported to WHO as of 30 June 1996. - Cas de SIDA signalés à l'OMS au 30 juin 1996.

^b Excluding USA. - Sauf États-Unis.



Map 1 Estimated cumulative distribution of HIV-infected persons from late 1970s/early 1980s until mid-1996

Carte 1 Estimation de la répartition cumulée des personnes infectées par le VIH depuis la fin des années 70/début des années 80 jusqu'à la mi-1996



Global total: ^a 27.9 million. - Total mondial: ^a 27,9 millions

^a Totals may not add due to rounding. - Les chiffres ayant été arrondis, leur somme ne correspond pas nécessairement au total.

Source: Joint United Nations Programme on HIV/AIDS. - Programme commun des Nations Unies sur le VIH/SIDA

Map 2 Estimated distribution of persons living with HIV/AIDS as of mid-1996

Carte 2 Répartition estimée des personnes vivant avec le VIH/SIDA à la mi-1996



Global total: 21.8 million. - Total mondial: 21,8 millions

* Totals may not add due to rounding. - Les chiffres ayant été arrondis, leur somme ne correspond pas nécessairement au total.
 Source: Joint United Nations Programme on HIV/AIDS. - Programme commun des Nations Unies sur le VIH/SIDA.

As of mid-1996, it is estimated that around 25.5 million adults, and more than 2.4 million children, have been infected with HIV since the beginning of the pandemic (late 1970s to early 1980s). *Map 1* presents the estimated regional distribution of total HIV infections in adults and children to date.

Map 2 shows the estimated regional distribution of these HIV-infected adults and children (including AIDS cases) alive as of mid-1996.

Currently, an estimated 21 million adults and 800 000 children are living with HIV/AIDS.

Zoonoses control

Equine morbillivirus in Queensland

Australia. The equine morbillivirus (EMV) was isolated in September 1994 by the Australian Animal Health Laboratory, the Queensland Department of Primary Industries' (DPI) Animal Research Institute and the Queensland Department of Health. The isolation of this virus was achieved as part of an emergency disease outbreak investigation conducted by the Queensland DPI.

Fourteen horses died as a result of infection with EMV in south-east Queensland during September 1994. A further 7 horses were shown to have been infected by the virus and, to avoid possible relapses in these horses, they were humanely destroyed. The first death attributed to the infection was a mare dying on 9 September 1994 after a short illness (first noticed to be ill on 7 September). The virus produced very severe damage to the lungs with the accumulation of massive amounts of fluid.

Two people who had close contact with the sick mare became infected with the virus and also suffered respiratory illness, in one case with fatal consequences.

A la mi-1996, on estime que plus de 25,5 millions d'adultes et plus de 2,4 millions d'enfants ont contracté l'infection à VIH depuis le début de la pandémie (fin des années 70/début des années 80). La *Carte 1* donne la répartition régionale actuelle de l'ensemble des infections à VIH chez l'adulte et l'enfant.

La *Carte 2* indique la répartition régionale estimée des adultes et des enfants infectés par le VIH (y compris les cas de SIDA) encore vivants à la mi-1996.

Actuellement, on estime que 21 millions d'adultes et 800 000 enfants vivent avec le VIH/SIDA.

Lutte contre les zoonoses

Le morbillivirus équin au Queensland

Australie. Le morbillivirus équin (MVE) a été isolé en septembre 1994 par l'*Australian Animal Health Laboratory*, le *Queensland Department of Primary Industries* (DPI) *Animal Research Institute* et les autorités sanitaires du Queensland. Ce virus a été isolé dans le cadre de l'enquête d'urgence faite par le DPI du Queensland sur une flambée de maladie.

En septembre 1994, 14 chevaux sont morts d'une infection due au MVE dans le sud-est du Queensland. Sept autres chevaux se sont avérés avoir été contaminés par le virus et, pour éviter tout risque de rechute, ils ont été abattus sans souffrance. Le premier décès attribué à l'infection est survenu chez une jument le 9 septembre 1994, à la suite d'une brève maladie (celle-ci avait été constatée le 7 septembre). Le virus avait entraîné de très graves lésions pulmonaires avec accumulation massive de liquide.

Deux personnes qui avaient été en contact étroit avec la jument malade ont été contaminées par le virus et ont également souffert d'une maladie respiratoire, qui a eu, dans un cas, une issue fatale.

14

MATERIAL ON HIV/AIDS

SENT BY

MEDICAL MISSION INSTITUTE

AIDS AND INTERNATIONAL HEALTH DEPARTMENT

SALVATORSTR. 22

D-97074 WÜRZBURG

GERMANY

13.1.1.157

AIDS-related policies, legislation and programme implementation in India

SHEENA ASTHANA

Department of Social Policy, Faculty of Human Sciences, University of Plymouth, UK

This paper traces the evolution of AIDS-related policy and legislation in India from an initial response characterized by conservatism and discrimination to the development of a coherent national programme which aims to prevent the transmission of HIV and to develop support structures for people with HIV and AIDS. Examining the strategies, achievements and problems of specific components of the National AIDS Control Programme (NACP), the paper finds that the very progressive approach of national-level policy makers has been countered by conservative forces at the state and local levels. Little progress has been made, moreover, in incorporating HIV/AIDS prevention efforts into broader development and empowerment strategies. The paper concludes by considering the wider social context of AIDS in India and the role of more far-reaching policy measures.

Introduction

In response to demands from both international agencies and indigenous organizations, the Government of India (GOI) is reviewing public policy and legislation relating to HIV and AIDS. During the 1980s, the official response was largely one of denial and complacency, with AIDS being regarded as a problem confined to foreigners and highly marginal groups. Although the National AIDS Control Programme (NACP), launched in 1987, was responsible for health education and care as well as screening and surveillance, in the Programme's early years more emphasis was placed on surveying so-called high-risk groups for HIV antibodies than on raising general awareness about the disease and developing support structures for those with HIV or AIDS. The lack of attention given to prevention during this period reflected both cultural taboos surrounding sexual behaviour in India (which gave rise to a reluctance to admit that heterosexual poly-partnerism and homosexual relations were not confined to highly marginalized groups) and the tendency for Indian health personnel to view AIDS as a *medical* problem. The subsequent neglect of the socio-cultural and economic context of HIV transmission left planners poorly equipped to design and implement HIV prevention strategies.

Since the creation in 1992 of the National AIDS Control Organization (NACO) and the expansion of NACP into the National AIDS Prevention and Con-

trol Programme, AIDS-related policy in India has evolved rapidly and progressively. According to current policy, all sections of society are to be targeted rather than groups at increased risk of infection only. NACP now acknowledges the need to promote greater awareness amongst the public as a whole, to ensure a policy of non-discrimination towards individuals with HIV or AIDS, and to focus more resources upon HIV prevention activities.

Whilst the government's response to AIDS has undoubtedly changed for the better, the extent to which its new rhetoric can be translated into reality remains to be seen. In addition to facing ideological barriers to change, attempts to implement the new policy objectives have been frustrated by practical and logistical problems. Bureaucratic inertia, for example, has prevented the desired collaboration between central and state governments; different ministries and departments; and between governmental and non-governmental organizations. As a result, the Programme has faced bottlenecks in the distribution of funds for AIDS projects, the recruitment of personnel and in the design and implementation of multisectoral strategies for HIV prevention and care.

The structure and organization of the health system in India also poses problems for AIDS policy-makers. The vast majority of the nation's doctors, who work in the private sector, are distanced from Central Government recommendations and initiatives; and,

notwithstanding the official commitment to primary health care, public health services (such as health education and community health) are under-developed. Finally, the practical difficulties of gaining access to vulnerable groups, such as commercial sex workers and intravenous drug users, have been compounded by a legislative context that reinforces their stigmatization and marginalization.

Against this background, this paper examines the strategies, achievements and problems of HIV/AIDS policy in India. Following a brief overview of the pattern of HIV transmission in the country, the evolution of policy and legislation relating to HIV/AIDS is described, with particular reference to the development of the National AIDS Control and Prevention Programme. In the third part of the paper, seven specific components of the Programme are identified and their objectives, achievements and problems assessed. These are programme management; surveillance; HIV prevention through information, education and communication (IEC); the control of sexually transmitted diseases; condom programming; blood safety; and the reduction of the impact of HIV/AIDS. The paper concludes by considering the wider social context of HIV/AIDS and the role of more far-reaching policy measures.

HIV transmission in India: recent trends

Although numbers of recorded cases of HIV and AIDS in India are still relatively low, the rapid increase in seropositivity rates amongst sentinel populations suggests that the scale and pace of HIV transmission in the country is already significant. By March 1995, 2 505 704 people in India had been screened for HIV infection. 18 222 were found to be seropositive using the Western Blot method and 1108 individuals have developed full blown AIDS (NACO 1995). Seventy-nine per cent of recorded HIV positive cases are located in the four states of Maharashtra, Tamil Nadu (including Pondicherry), Manipur and Karnataka (Figure 1). This partly reflects the more advanced medical and screening facilities in Bombay, Madras, Vellore and Bangalore. Thus, if the data are adjusted to take account of numbers screened, high prevalence rates are also found in the southern states of Goa, Kerala and Andhra Pradesh, together with Uttar Pradesh, Punjab/Chandigarh and Delhi in the north (Figure 2). Significantly, 24 of the states or union territories in the country have already reported HIV infection.

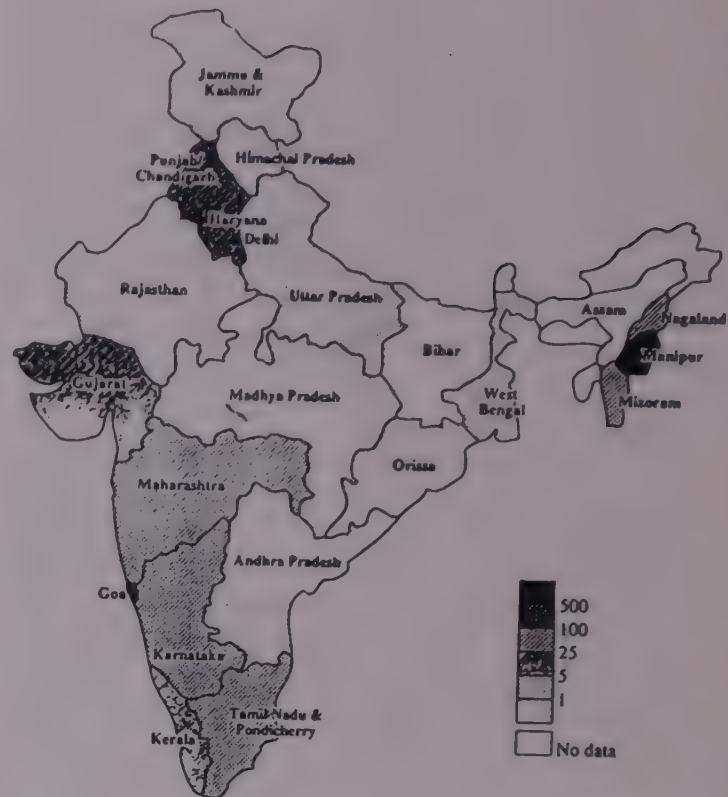


Figure 1. Recorded HIV positive cases per million population, India, May, 1995



Figure 2. HIV positive cases per 10 000 cases screened for HIV infection, India, May, 1995

The dominant mode of HIV transmission in India is heterosexual intercourse. The strong double standard that expects women to preserve their premarital virginity and to remain exclusively faithful to their husbands, but which tacitly accepts that men may engage in premarital or extramarital intercourse, has resulted in a sizeable demand for female prostitution. At the same time, there are large numbers of impoverished women who find few opportunities for economic survival other than commercial sex. Up to one million women are estimated to work in the Indian commercial sex industry (ICMR 1992), 100 000 in Bombay alone. Low levels of condom use and high rates of client turnover have facilitated the transmission of sexually transmitted diseases, including HIV. Approximately 30% of prostitutes in Bombay are believed to be HIV positive (ICMR 1991) and in Madras, where the first case of HIV infection in the country was detected, seroprevalence levels amongst commercial sex workers had reached 15% by June 1993 (personal communication, Dr Jayapaul).

Intravenous drug use has also emerged as an important risk factor of HIV transmission in India. The highest rates of HIV have been recorded in the north eastern state of Manipur where cheap and easily available good quality heroin is fuelling an HIV epidemic amongst intravenous drug users, or IDUs (Naik et al. 1991). By March 1995, 97 per 1000 people screened in the State were found to be HIV positive, yielding a seroprevalence rate of 171 per 100 000 population (NACO 1995). The neighbouring states of Mizoram and Nagaland are also recording steady increases in HIV. High rates of injecting drug use in this region have been associated with its proximity to the 'Golden Triangle' of Burma, Laos and Thailand where 20% of the world's heroin is estimated to be grown and processed. However, intravenous drug use is not confined to the north east. Of the estimated 2 million drug users in India, 50 000 are believed to inject drugs (Jayaraman 1992). In Delhi the recorded seropositivity rate amongst IDUs rose from 43.5 per 1000 in 1993 to 333.3 in the first 6 months of 1994 (*Pioneer* 1994).

Whilst trends in HIV prevalence amongst commercial sex workers (CSWs) and IDUs have commanded the most attention of both the Indian media and government officials, evidence suggests that HIV is firmly entrenched in the general population. The number of people who have been infected by blood and blood products is unknown, although this factor

currently accounts for more full-blown AIDS cases in India than intravenous drug use. CSWs and their clients also provide a point of contact for HIV transmission between large numbers of otherwise disconnected people. As a result, growing rates of seroprevalence are being observed in so-called low-risk groups. Extrapolating data on HIV prevalence rates in pregnant women and blood donors, GOI and WHO suggest that the AIDS epidemic in India will exceed that of neighbouring Thailand. By the end of 1992 more than one million people in the country were estimated to be infected with the virus. This figure is expected to double or even triple by 1996 (NACO 1993).

The evolution of HIV/AIDS policy in India

During the early 1980s, the official response to AIDS in India was one of denial (Girimaji 1990; Chatterjee 1991). AIDS was seen as a 'foreign' disease from which ordinary Indians would be spared. The detection, in 1986, of HIV antibodies in Indian CSWs did little to dispel this belief. Although women engaged in prostitution were vilified for 'importing' the disease by having sex with foreigners and were identified as a potential 'reservoir of infection' which threatened the general population, the stigmatization of CSWs served to distance them from an indifferent public and to reinforce the view that AIDS was restricted to specific, well-defined groups. This view prevailed when cases of seropositivity were identified in 1987 amongst professional blood donors. Rather than using this sample (albeit biased towards impoverished men) to interpret possible trends in HIV infection in the general population, professional blood donors were branded a 'high risk group' and charged with sexual promiscuity and drug addiction.

The emphasis placed upon high-risk groups rather than high-risk behaviours both reflected and contributed to the first policies and laws relating to HIV/AIDS. In 1986 the Indian Council of Medical Research (ICMR) in collaboration with the Directorate General of Health Services (DGHS) and individual State Governments initiated a national programme of serological surveillance (ICMR 1987; ICMR 1988). This provided the springboard for (indeed, came to be synonymous with) the National AIDS Control Programme which was formally launched in 1987. Rather than developing a system of sentinel surveillance, efforts focused on the unsystematic collection of samples from 'high-risk'

groups. The latter were defined as sexually promiscuous men and women, homosexuals, IDUs and people who had received repeat blood transfusions. However, as little guidance was given with regard to the practical problem of identifying and testing such individuals, samples were taken from 'captive' populations (STD patients, women detained under the prostitution laws, blood donors and hospital patients). As access to the latter depended upon the extent to which individual Surveillance Centres could liaise with hospitals and social welfare or police departments in their states, there was a large variation between the centres in both the numbers of individuals and the proportions of specific groups tested. By October 1989, for example, Tamil Nadu State alone accounted for 43% of all people screened in India. By contrast the State of Uttar Pradesh, which comprises 16% of the total Indian population, had tested less than 2% of all screenees.

As targeting procedures clearly differed from centre to centre and state to state, it became difficult to draw reliable conclusions about the prevalence of HIV in specific groups or regions, let alone piece together a national picture. However, ICMR felt compelled to publish its findings. With insufficient information to assess the prevalence, distribution and likely spread of HIV in the population as a whole, the Council could do little more than draw the public's attention to its sero-surveillance data on high-risk categories. Such selective reporting inevitably reinforced the impression that AIDS was restricted to the most marginalized of groups and strengthened calls for discriminatory legislation.

During the 1980s, various legal measures were proposed to prevent the so-called importation and spread of HIV in India, from compulsory testing to the isolation of HIV positive individuals and AIDS patients. Despite popular support, most were rejected on the basis of human rights. The notorious AIDS Prevention Bill of 1989, for example, gave government and health authorities sweeping powers to infringe upon individual rights (de Souza 1990). The draft Bill included provisions to require medical practitioners to notify local health authorities about any drug addicts, HIV positive people and AIDS patients in their care; to empower health authorities to forcibly test and question individuals suspected to be at greater risk of infection and isolate HIV positive cases; and to introduce criminal penalties for the transmission of HIV by professional blood donors. Not surprisingly, the Bill received

widespread criticism for victim blaming and denying human rights and, following a series of amendments, it was finally withdrawn in 1992.

The absence of legislation has not prevented the application of highly discriminatory measures in practice. Questions have been raised, for instance, about the methods used in surveillance activities. Although the collection of blood samples from high-risk groups is technically 'voluntary', it is doubtful whether the consent of screened individuals is always obtained and whether they have the knowledge and freedom to refuse testing. Other problems relate to the treatment of individuals found to be HIV positive. Information about people's HIV status is frequently leaked to the press who have not only named HIV positive individuals, but printed their photographs. A number of states have illegally detained HIV and AIDS sufferers as well as people suspected to be at high risk of infection. In 1988, for example, HIV positive sex workers arrested under the Prevention of Immoral Traffic Act in Madras were kept under detention even after serving their official sentences. The case provoked a strong response from local activists and in 1990 the Madras High Court ordered the release of five prostitutes who had been detained at the Government vigilance home (Nataraj 1990).

In the face of both international and national pressure, GOI began to revise its AIDS policies. In 1989 a medium-term plan for AIDS control was drawn up in collaboration with WHO. This focused on the need to establish an effective programme management structure with a view to coordinating multisectoral policies. In 1990 responsibility for surveillance activities was transferred from ICMR to the office of the National AIDS Control Programme in DGHS (NACO 1993). As the latter had already initiated blood safety and AIDS case management programmes (whereby existing medical colleges and institutes had been designated as regional centres for the clinical treatment of AIDS), this paved the way for the creation of an umbrella organization responsible for coordinating a broader range of AIDS-related policies. In 1991, proposals for a new bureaucratic structure encompassing such an organization were developed in a 5-year Strategic Plan for the Prevention and Control of AIDS in India. The following year, the National AIDS Control Organization was officially established and the more comprehensive National AIDS Prevention and Control Programme was launched.

The creation of NACO represented a turning point in Indian AIDS policy. Although some emphasis is still placed on surveillance, NACP now acknowledges the need to focus more resources upon HIV prevention strategies as well as counselling and care. To this end, the Programme aims to encourage safer sex practices and condom use amongst the general public as well as vulnerable groups; to further develop STD (sexually transmitted disease) prevention and control activities; to ensure that HIV positive individuals and AIDS patients are provided with care, counselling and support in order to live their lives in dignity; and to integrate AIDS Information, Education and Communication (IEC) programmes with existing health programmes, including mother and child health and family planning, and with other sectoral programmes in education, youth affairs, women's issues, welfare, urban development and labour affairs. In order to implement this comprehensive approach, NACO explicitly calls for intersectoral and NGO (non-governmental organization) collaboration together with grassroots mobilization.

NACO suggests that grassroots approaches are particularly relevant to the development of targeted programmes for groups practising high-risk behaviours (sex workers, their clients and employers; IDUs; men who have sex with men; school leavers; migrant labourers and prison inmates) and identifies NGOs as major partners in such initiatives. It accepts that no standard formula can be applied to community-based strategies and that programmes should be adapted to local level circumstances. In the absence of detailed knowledge about the socio-demographic characteristics and social structures of vulnerable groups such as CSWs and IDUs, the need for qualitative assessment of local needs and potential strategies is also acknowledged (Government of India 1991).

With its commitment to project integration, community participation and non-governmental involvement, GOI's response to AIDS has undoubtedly changed for the better. However, the 5-year Strategic Plan is ambitious and problems of translating policy into practice in the Indian context may have been underestimated. The following section examines NACP's specific components in more detail and considers factors that have enabled and constrained their implementation.

The National AIDS Control Programme: specific components

As outlined above, AIDS policy in India prior to 1992 focused almost exclusively on serosurveillance. Between 1987 and 1991, 85% of the national AIDS budget was devoted to the screening of individuals, blood and blood products (NACO 1993). By contrast, in 1992 there were only five government centres for the care of AIDS patients in the whole of the country (Baweja and Katiyar 1992). Health education activities were also woefully inadequate and relied on the limited number of non-governmental organizations who were willing to work in AIDS prevention. Recognizing the need to focus resources more effectively on preventive activities, NACP incorporated an IEC component, STD control and condom promotion in addition to the existing surveillance and blood safety programmes. Strategies for reducing the impact of HIV and AIDS were also included in the new plan. In order to implement this more extensive range of activities, attention to and funds for programme management were substantially increased.

Strengthening programme management

As NACP objectives and activities, together with the budget available for HIV/AIDS policy, have expanded, the management demands of the Programme have become significantly more complex. On the one hand, a centralized management structure is required to provide overall policy directions, to coordinate multisectoral collaboration, to extend technical and operational support to staff and organizations implementing programme activities, and to approve budgets and disburse funds. At the same time, there is an increasing awareness of the role of regionally specific factors in the transmission of HIV and thus of the need for management to be decentralized so that appropriate action can be taken by state and district authorities and by local NGOs. Political pressures have also propelled the decentralization of AIDS programme management to the state level. Health is constitutionally a state responsibility in India and individual states have considerable power to either accept or reject centrally organized and centrally funded programmes. It is therefore both necessary and desirable for state governments to fully participate in the design, implementation and management of the country's AIDS programme.

The new National AIDS Control Programme has a hierarchical structure, each level of management

corresponding with a level of bureaucracy in the state machinery. The National AIDS Control Organization (NACO) is accountable to and receives policy guidelines from multisectoral committees chaired by the Minister and Secretary of Health. Nevertheless, it holds sufficient administrative and financial powers to constitute a centralized body for the planning and management of policies relating to HIV and AIDS. It is at this level that specific programme components are designed, coordinated and monitored; that funds are allocated and disbursed; and that liaison takes place with associated ministries, state governments, multilateral and bilateral agencies and NGOs. All government ministries and departments, for example, have been invited to designate officers responsible for developing programmes in collaboration with the Organization. NACO is also supported in its functions by a National Technical Advisory Committee which endorses operational guidelines and which may advise on the need for training and educational materials.

In order to decentralize the planning, implementation and management of AIDS prevention programmes to a more appropriate level, the basic organizational structure of NACP has been replicated at the state level. State AIDS Control Programmes are managed by State AIDS Cells (the counterparts of NACO), which are supported by State Technical Advisory Committees and overseen by Empowered Committees. Like their national level counterparts, the latter are expected to have multisectoral representation so that partners from various government sectors, industry, women's groups, NGOs, trade unions and so on can contribute to the development of strategic plans. Arguing that the factors associated with HIV transmission vary regionally, NACP envisages that each state will develop its own approach to AIDS prevention and control. To this end, the involvement of NGOs is strongly encouraged as such organizations tend to have the freedom and flexibility to respond to local needs.

The new organizational structure of NACP demonstrates a commitment by the Government of India to mount a serious response to the growing challenge of AIDS by fostering collaboration between central and state governments, different ministries and departments, and between governmental and non-governmental organizations. In practice, however, this has proved hard to achieve. The most serious setbacks to the Programme have occurred at the state level, due to the failure of state governments to

observe NACO directives and to promote the participation of the NGO sector. Between 1992 and 1993, 22 states and union territories used less than 10% of the funds allocated to them for AIDS prevention and control. Several state governments failed to create AIDS Cells and in some cases money was diverted to other programmes. Even where AIDS Cells have been established there have been problems with staff recruitment and programme implementation. Staff are normally transferred to the Cells from health and other government departments. However, because AIDS Cell posts are perceived to have a limited life-span (they are supported from a five-year World Bank loan) and because of the stigma attached to AIDS-related work, these appointments are treated like 'punishment postings' (*Pioneer* 1993). By July 1993, only three of the 11 vacancies in the Delhi Cell had been filled, and in the Punjab officers were reshuffled every three months. Such procedures are unlikely to result in an efficient and dedicated staff.

Problems have also emerged in programme implementation, most particularly in attracting NGO involvement in the design and implementation of HIV prevention activities. Contrary to national guidelines, very few state governments (Tamil Nadu being a notable exception) have created Empowered Committees with multisectoral representation. The absence of NGO participation in management has done little to counter bureaucratic conservatism in policy development and resource allocation. For example, rather than placing funds directly at the disposal of the new State AIDS Cells, Finance Departments have typically released the money to Health Departments. The latter have proved reluctant to support programmes of a more innovative nature and to support the non-governmental sector. In response to demands from NACO and the Ministry of Health, state governments have begun to review their funding procedures. In metropolitan cities, for example, efforts are being made to set up separate administrative departments within municipal corporations (NACO 1994). These umbrella organizations would plan and coordinate the implementation of AIDS prevention and control activities by different agencies and sectors.

The creation of umbrella organizations at the city and state levels would be a positive development for NACO's aim of promoting integrated HIV/AIDS policies. The Organization recognizes that this disease cannot be addressed by the health sector alone. However, although it has had some success in

establishing intersectoral collaboration at the national level, this has not brought about the desired shift towards a more comprehensive approach to HIV and AIDS. Good examples of collaborative ventures include the incorporation of HIV/AIDS awareness activities into the 'Universities Talk AIDS' programme (implemented by the National Service Scheme of the Department of Youth Affairs and Sports of the Ministry of Human Resource Development (HRD), and developed with close collaboration between NACO, the Ministry of HRD and WHO) and the allocation of free prime time on national television for HIV/AIDS awareness campaigns. These and other planned collaborative efforts are very positive developments, given the need for integrated approaches to HIV/AIDS prevention. However, they are also highly selective in orientation, reflecting the continued tendency to conceptualize HIV transmission in terms of individual behaviour rather than social change. In order to be effective, HIV intervention strategies must focus upon the social, cultural and economic factors that give rise to risk behaviours in the first place and that constrain less risky activity. To date, however, little progress has been made in incorporating HIV/AIDS prevention efforts in India into broader development and empowerment strategies.

HIV/AIDS surveillance

Some of the problems of the surveillance programme have been discussed above. These include the lack of a systematic sampling strategy, wide regional variations in numbers and proportions of different categories screened, inconsistencies in the reporting and processing of data, and the lack of attention paid to ethical issues such as consent and confidentiality. ICMR began to acknowledge the limitations of its data in 1990 (ICMR 1990). However, responsibility for surveillance activities has filtered down to the state level and, due to bureaucratic inertia, the structure and mechanisms of the programme have remained largely unchanged. The vast majority of samples continue to be drawn from so-called 'high-risk' groups with sample collection depending upon individual centres' targeting procedures and access to captive populations. As a result, screening efficiency and intensity vary widely. In Delhi, for example, the percentage of positive samples collected by 8 centres which had screened more than 10 000 individuals by June 1994 ranged from 0.0003 to 0.05. The pattern of surveillance is also highly uneven at the state level, rates of screening by March 1995 ranging from 6868

per 100 000 population in Pondicherry to 10 per 100 000 in Bihar.

In addition to yielding data of doubtful reliability, the surveillance programme has come under attack for infringing human rights. India is a signatory of the World Health Assembly resolution which calls upon governments to protect from discrimination persons or groups known or suspected to be HIV positive. To this end, NACO has requested that states organize a sound and rational testing policy which includes unlinked anonymous testing for surveillance and screening of blood; linked testing for those with acute symptoms of AIDS where counselling is available; and voluntary testing facilities only in the presence of sound counselling and support services. In practice, many samples collected for surveillance are linked (indeed, names continue to be leaked to the press) and although testing is technically voluntary, many of those screened have neither the knowledge to give informed consent or the freedom to refuse to be tested. Counselling of HIV positive individuals is inadequate, amounting to little more than post-test advice on how to avoid infecting other people and little is available in the way of social, psychological and medical support.

Acknowledging the failings of the surveillance system, NACO has decided to adopt a sentinel surveillance system whereby in a limited number of selected sentinel sites, selected populations will be screened for HIV prevalence at certain intervals to monitor the progression of the epidemic and to identify trends. A standardized protocol for sentinel studies has been developed and introduced. Efforts are also underway to improve the quality of counselling offered to people with HIV and STDs. To this end, a grassroots counselling training module has been developed and a counselling training programme established with appropriate modules and manuals.

Behavioural change through information, education and communication

Because the dominant mode of HIV transmission in India is heterosexual intercourse, strategies to modify sexual behaviour are a key component of HIV prevention. Nearly a decade after HIV infection was first detected in an Indian national, there is little evidence to suggest that such behavioural change has been achieved. Levels of knowledge and awareness about HIV and AIDS are very low in both the general population and vulnerable groups; condoms have a negative image and are almost exclusively associated

with family planning; and, as sexual relations are inherently unequal, few women have the power to protect themselves against HIV.

During the earlier phase of the National AIDS Control Programme, cultural taboos about openly discussing sex fostered a reluctance to initiate AIDS awareness campaigns. Official apathy and indifference were also linked to the belief that AIDS would be confined to highly marginalized groups. Notwithstanding such cultural sensitivities, NACO now recognizes that there is a pressing need for activities designed to generate awareness about HIV and AIDS and to bring about changes in risk behaviours. To this end, the Organization is disseminating information about AIDS through the television, radio, press and other channels of communication. The 'Universities Talk AIDS' programme currently reaches approximately 10 million students in 6500 colleges and universities in India. Efforts are also underway to devise educational materials for members of the services, railway workers, industrial workers and prisoners (Dasgupta 1994).

Until recently, attempts to introduce AIDS education to schoolchildren proved unacceptable to educationalists who believed that sex and AIDS education would encourage early sexual experimentation (Muley 1994). However, an extra-curricular package on HIV/AIDS and STDs has now been developed by the National Centre for Education Research and Training (NCERT) in collaboration with NACO, UNICEF, UNESCO and WHO. This package has been discussed by various groups, including teachers and parent-teacher associations, and forms the basis for proposals from 15 states for school-based AIDS awareness programmes.

In addition to general awareness campaigns, NACO is promoting the development of HIV prevention programmes to bring about behavioural change in highly vulnerable groups such as CSWs and their clients. Targeted interventions are a recent development in Indian AIDS policy. Nevertheless, a number of ambitious pilot projects have been initiated with technical assistance from WHO. In Madras, for example, a pilot scheme was established in 1992 for the design and implementation of IEC strategies amongst members of the commercial sex industry (Asthana and Oostvogels, forthcoming). Due to the isolation and powerlessness of sex workers themselves, the recruitment of peer educators proved problematic. The project therefore tested strategies which

involved close affiliates of the target groups. These included madams, pimps and brothelkeepers. It also recognized that it was important to include clients in outreach efforts since their cooperation in using condoms is essential. Brokers (who procure clients for CSWs) were identified as a potential conduit for the dissemination of AIDS information and condoms amongst this target group. Finally, the cooperation of a wide range of players with more peripheral links with the sex industry was enlisted. These included local police; general practitioners who provide STD services; the employees of cinemas, wine shops and bars; political and religious leaders; and the local media.

By endorsing community-based strategies of this type, NACO is in tune with international AIDS policy. Nevertheless, there remain powerful obstacles to promoting behavioural change amongst targeted groups. Official attitudes to CSWs, for example, are still highly contradictory. The Suppression of Immoral Traffic Act of 1956 (SITA), amended in 1986 (PITA), did not originally seek to abolish prostitution, but to abolish the practice of exploitation of women by others. However, the client is not an offender under the Act and sex workers can be penalized under Sections 7 and 8 for soliciting (Singh 1991). In practice, moreover, it is prostitution rather than exploitation that is targeted for legal action with over 90% of the 15 000 or so cases that are registered annually under SITA/PITA being taken against sex workers rather than pimps and procurers (personal communication, Dr R Oostvogels).

Vulnerable to stigmatization and criminal prosecution, it is hardly surprising that CSWs remain suspicious of official involvement. Confidence has been expressed in the ability of NGOs to gain access to marginalized groups. However, care should be taken in assuming that the non-governmental sector is, by definition, more virtuous than its governmental counterpart. Evidence suggests that a growing number of Indian NGOs which have jumped on the AIDS bandwagon are motivated by self-promotion rather than altruism. Many organizations would appear to be more interested in attracting international funds and attending international conferences than working in the communities they claim to serve. Finally, NGO projects that have been initiated with outside assistance may not prove sustainable once that assistance has been withdrawn.

Other obstacles to the promotion of behavioural change stem from the nature and organization of the

commercial sex industry itself. Whilst street workers are fairly visible because of where they work, other CSWs are engaged in disguised prostitution and are thus difficult to identify. Women who continue to live in regular households but who sell sex without the knowledge of their families and neighbours maintain a close secrecy about their working lives. It can also be difficult to gain access to brothel-based women. In Madras, for example, the premises in which brothels are housed regularly shift in response to police raids or complaints from neighbours. Information about the location of brothels is thus restricted to regular clients and brokers (Asthana and Oostvogels, forthcoming).

Finally, HIV prevention strategies are undermined by the powerlessness of commercial sex workers. Improved access to condoms has a limited impact on sexual practices if targeted individuals cannot insist upon their use. Yet, evidence suggests that it is the client rather than the sex worker who determines condom use and the few client surveys that have been undertaken in India reveal very little enthusiasm for safe sex. Brothel owners can play a key role in defining the sexual practices of the women they control and may be persuaded that there are business advantages to being able to advertize safe sex. In practice, however, many brothel owners will put the immediate needs of their clients before those of CSWs, and if condom promotion is perceived to threaten client interest and satisfaction, they will not insist upon condom use.

Control of sexually transmitted diseases

The prevention and control of sexually transmitted diseases (STDs) is recognized as one of the major strategies of HIV prevention as genital ulcer diseases and STDs characterized by discharge facilitate both the acquisition and transmission of the HIV virus. Official data on STD prevalence rates in India are limited as they are based on cases reported to public hospitals and STD clinics. Evidence suggests that only a very small percentage of STD sufferers attend public facilities, the majority seeking clinical care from private doctors, going directly to drug sellers (where both diagnosis and case management tend to be inadequate) or resorting to self-medication. Women are particularly likely to go without treatment; first because women with STD are frequently asymptomatic, second because they may not be aware of the significance of genital tract symptoms, and third because of the fear and stigma attached to seeking care for an STD. Those in rural areas are further

disadvantaged due to the lack of female doctors and problems of physical access to health facilities. Recent evidence also suggests that because women who do seek treatment are often too inhibited to be physically examined, health workers are forced to rely on verbal accounts (Ramasubban 1990). This clearly increases the risk of misdiagnosis.

As a first step towards developing STD prevention and control activities, NACO has commissioned a number of baseline surveys to evaluate the extent of the problem. In Tamil Nadu, samples were collected from selected populations in 1992. Rates were highest amongst female remand prisoners (a group likely to comprise a high proportion of CSWs), 36% of whom were infected. However, 10% of antenatal clinic attenders were found to suffer from a sexually transmitted disease and 2% from syphilis. STDs were also found to be a significant problem in rural areas, with 6% and 4% of men and women being affected. Four percent of rural men were found to suffer from syphilis (NACO 1993). These figures suggest that STDs constitute a major health problem in India and that large numbers of people in the country are potentially at risk of contracting HIV.

Recognizing the severity of the problem, NACO has proposed that, in addition to offering technical assistance to individual states and union territories, central funds are to be channelled into STD prevention and control efforts. A national STD programme has been in existence since 1946. However, during the first two decades of the programme, health officials were more preoccupied with combating major epidemic diseases such as smallpox and malaria. Because STDs were regarded as less life threatening, they commanded a lower medical and administrative priority (Arnold 1993). In the 1960s and 1970s STD clinics began to be established at both state and district levels. However, rather than developing community approaches to STD prevention, emphasis was placed on diagnosis and treatment.

NACO has proposed that policies need to be aimed at both preventing STD infection and providing better diagnosis and case management of these diseases. To this end, it is developing IEC strategies which promote safer sex and condom use. Prevailing attitudes to STDs need to be challenged as high-risk groups are more likely to rely on antibiotics to cure venereal disease than methods to prevent it in the first place. Many brothel owners, for instance, arrange for their girls to have weekly injections of antibiotics from

private doctors. This may promote complacency amongst sex workers who come to believe that HIV, like other STDs is curable. Even when efforts are made by sex workers and their clients to prevent STD transmission, evidence suggests that they place their faith in folk remedies and myths rather than condoms. Qualitative research undertaken by a WHO-funded team in Madras found that many sex workers believed that washing one's genitals after intercourse in urine, soda water or lime juice would prevent STDs. Another idea was that whilst intercourse by a roadside or railway track encourages the spread of disease, sex in a confined room does not (Asthana and Oostvogels, forthcoming). Such ideas act as barriers against the use of condoms and suggest the health education regarding STDs and AIDS is a priority.

In addition to raising knowledge and awareness, NACO aims to improve access to health care for sexually transmitted diseases by strengthening existing facilities and by extending STD services to non-specialist centres (such as MCH/Family Planning and antenatal clinics). Staff at the existing 372 STD clinics in medical colleges and hospitals are to receive laboratory equipment and training in diagnosis, case management, surveillance, education and counselling. Under the new policy, however, the emphasis has shifted away from these higher order centres and from the laboratory diagnosis of STDs, to first level health workers and the use of the syndromic approach to the management of people with STDs and their partners. Thus, although STD clinics will play a role in training paramedical personnel and will act as referral centres for the diagnosis and management of difficult cases, the STD programme will be decentralized to the primary level. Efforts are also underway to provide orientation and training for private health care providers. This is one of the most difficult aspects of the component, first because of the size of the private sector and second because the STD training modules are likely to attract doctors who already have some interest, knowledge and awareness about STD case management. The participation of medical staff who are providing poor quality STD services will be more difficult to achieve.

Condom programming

High rates of STDs amongst the general population and amongst sex workers in particular reflect very low levels of condom usage by sexually active individuals in India. Factors that have contributed to

the generally negative image that people hold about condoms include the tendency to associate STD control with cure rather than prevention, the poor quality of condoms sold on the Indian market, and medical attitudes and practices regarding family planning. Condoms are associated with contraception rather than disease prevention and are presumed to negatively affect sexual pleasure. As a result, they are rarely used in encounters between CSWs and their clients. Indeed, sex workers may be abused for insisting upon their use. For many clients, particularly those who hire the services of a prostitute with a group of friends, it is simply not macho to use a condom. Sex workers also hold negative beliefs about condoms, such as the fear that they might get lost in the vagina or that they will prolong the sexual encounter. Health education is needed to counter such beliefs. Thus, targeted IEC strategies incorporate condom promotion as a central component.

Negative attitudes amongst potential users also stem from the belief that condoms are not particularly effective. Experiences of breakage are not uncommon and are usually due to poor condom quality. NACO has therefore undertaken to improve the quality and image of condoms available on the Indian market (including the Government's own brand, 'Nirodh'). A major legislative achievement has been to revise Schedule 'R' of the Drugs and Cosmetics Act which stipulates the statutory minimum quality standards for condoms manufactured in the country. Manufacturers are also required to improve their methods of quality assurance. Thus, the production and distribution of unlubricated condoms has been phased out (lubricants reduce friction and thus the likelihood of breakages) and better quality testing (e.g. for strength, ageing and holes) introduced. Methods of social marketing to increase demand amongst target populations are also being investigated. These include using packaging and advertizing to make condoms more exciting and distributing condoms through vending machines to reduce the embarrassment of purchasing them. More emphasis is also being placed on improving the commercial distribution of affordable condoms, first because freely distributed condoms are associated with the Government's family planning campaign and second because the sale of condoms tends to raise their value in consumers' minds.

In spite of the association that is commonly made between condoms and family planning, it is estimated that only 5% of eligible couples actually use this method of contraception. At present the most

popular forms of contraception advocated by family planning agencies are sterilization and intra-uterine devices (IUDs), followed by oral contraceptives and finally condoms. The emphasis on permanent or long-term methods of family planning stems from the lack of follow-up given to women, especially those who gain access to these services through large rural family planning camps. There is also a tendency amongst health professionals to assume that barrier methods are too unreliable to be widely promoted amongst low-income and illiterate groups. As a result, there is little demand for condoms in the general population.

The growing incidence of HIV in the country means that more emphasis needs to be placed on methods that achieve the dual purpose of family planning and disease prevention. Moreover, as IUDs are contra-indicated for women who are at risk of contracting STDs, including HIV, the active promotion of this form of contraception is not desirable. In an important example of inter-sectoral collaboration, NACO has coordinated with the Department of Family Welfare and the condom is now promoted as a 'dual benefit product', protecting against both conception and disease. Nevertheless, there remain important obstacles to improving the uptake of this method. Many women are not in a position to negotiate safe sex, either because they are under pressure to conceive or because it is culturally unacceptable for them to suggest the use of condoms, even to husbands with other sexual contacts. Couples wishing to practice birth control may also find condoms impractical if they lack privacy or if they cannot dispose of them easily.

Blood safety programme

Blood transfusion is the most efficient and also, at least in theory, the most easily preventable mode of HIV transmission. However, infected blood and blood products account for the second largest number of recorded AIDS cases in India (12%), preceded only by multiple partner sex (75%). HIV was first detected in a professional blood donor in 1987, after which surveillance centres were instructed to intensify screening of blood donors. The seropositivity rate in this group rose sharply from 0.3 per 1000 in April 1988 to 1.5 per 1000 six months later and in 1989 the screening of all donated blood and blood products became mandatory. Since 1990, 180 zonal blood testing centres have been established in 112 cities. These have established linkages with public, voluntary and private sector blood banks and any samples

sent to them which are found to be positive after the first ELISA test are discarded. As screening has become less biased towards metropolitan cities and towards professional blood donors, current rates of seropositivity are lower than found in initial studies. In 1991, 0.37 cases per 1000 donors screened tested positive. In 1992 this figure had risen to 0.85. In major urban centres, however, seropositivity rates amongst this sector have risen very steeply, rates of 22.9 and 23.1 per 1000 being recorded in 1992 in Bombay and Madras (NACO 1993).

The high risk status of professional blood donors is uncertain on the basis of risk *behaviour*. It is likely that samples have been double counted due to the tendency of professional blood donors to sell blood to different blood banks under different names (ICMR 1989). Commercial blood banks may also take several units from a single donor but use different names in order to evade regulations which state that individuals should donate no more than one unit every 12 weeks (Girimaji 1992). Both practices would be expected to inflate the seropositivity rate of paid donors. Nevertheless, sentinel studies have consistently recorded higher rates of HIV infection in professional than in voluntary and replacement donors. As most professionals are destitute, without kin and travel from city to city, it is sometimes suggested that they are more prone to visit prostitutes (Ramasubban 1990). Another possible explanation is that the process of plasmapheresis (whereby red blood cells are reinjected after separating and retaining liquid plasma) exposed professional blood donors to the HIV virus due to the inadequate sterilization of equipment (Girimaji 1992).

Although testing of all donated blood has been mandatory since 1989, three years later an estimated 85% of the nation's blood supply was not being screened for HIV (*India Today* 1992). Blood banks in smaller towns and cities lacked access to screening centres and few had the skills or equipment to undertake testing themselves. Whilst linkages had been established between zonal blood testing centres and government blood banks in metropolitan cities and large urban centres, many private blood banks were not sending their samples to be screened. The private sector includes commercial blood banks which in 1989 supplied 24% of the nation's blood supply and which are estimated to rely on professional blood donors for 94% of blood collected (NACO 1993). It is therefore likely that a significant proportion of infected blood has been missed by the screening

programme. There is also evidence to suggest that professional blood donors responded to the tightening up of screening procedures in metropolitan areas by migrating to smaller towns and cities.

Problems of blood safety are not confined to blood donated by professionals. Because demand for blood outstrips the public supply, relatives of patients requiring operations are encouraged to donate their own blood (replacement donations). HIV prevalence is also increasing in this group. In 1992 HIV prevalence rates of 6.7 and 8.2 per 1000 were recorded in voluntary and replacement donors in Maharashtra State, compared to 16.8 per 1000 in paid donors (Bharucha 1992). The rate in the replacement group may result from the practice of professionals posing as relatives if the latter are unwilling to donate blood. Nevertheless, it suggests that improvements in both the supply and the screening of blood must be made if HIV transmission is to be avoided during emergency surgery.

Recognizing the urgency of improving blood safety in India, NACO has undertaken to improve testing of blood and blood products, strengthen existing government facilities and external quality control, promote voluntary blood donation, develop and improve facilities for plasma fractionation, and to improve the management, monitoring and evaluation of blood transfusion services. Central funds will continue to support zonal blood testing centres, and district level blood banks which handle small quantities of blood are being provided with rapid HIV test kits. NACO is providing central assistance to states to upgrade blood banks in the public sector and the Drugs and Cosmetic Act has been amended to ensure that the Government has better control over the licencing and inspection of private blood banks. Before blood banks are to be granted a licence, they must be approved by the Drug Controller of India. Legal requirements introduced in the Act include qualification and experience requirements for blood bank personnel, mandatory testing of all blood and blood products, maintenance of complete and accurate records, and quality control. Blood Transfusion Officers have been appointed to coordinate the Programme's management at the State level and provision has been made for two drug inspectors in the major states and one in the smaller states to regulate the practices of blood banks. Voluntary blood donation is also being promoted through IEC strategies involving the mass media, government institutions and NGOs, and attempts are being made to educate

health professionals to use blood and blood products more rationally.

Improved surveillance of donated blood has already had an impact on HIV transmission through blood transfusions, at least in the metropolitan areas. According to the head of the Delhi AIDS Cell, the rate of infection in blood recipients had fallen from 20 per 1000 in 1993 to 10.5 per 1000 in 1994 (*Pioneer* 1994). However, there are formidable obstacles to ensuring that all donated blood is screened. Bottlenecks have occurred in the implementation of the Blood Safety Programme at the State level due to the failure of State Finance Departments to release centrally allocated funds and, as there remain acute shortages in the nation's blood supply, unregistered blood banks continue to operate. There is little comfort, too, for the thousands of people suspected to have been infected with HIV by blood or blood products. In 1994 a woman who received HIV infected blood at a charitable hospital in Bombay lost her claim for damages on the basis that she had been treated free of charge (*Times of India* 1994). It is likely that this court decision will set a precedent regarding compensation for people with HIV and AIDs.

Reduction of impact

Whilst efforts to prevent the continued spread of HIV have been stepped up since 1992, there are already sufficient numbers of infected people to have profound social, economic, medical and psychological impacts on affected individuals, their families and communities. Although NACO has said little about the social and welfare costs of a disease that predominately affects people in their prime productive and reproductive years, it has started to plan for the impact of AIDS in the health sector. Health costs of HIV/AIDS include increased demands on hospitals, medical staff and health budgets, together with new demands for counselling and psychological support.

Recognizing that the current health care delivery system will have difficulty coping with the projected numbers of people with AIDS, NACO has proposed the development of community and home-based care programmes in which family members are trained in basic nursing skills and hygiene, and are supported by community level workers and local health facilities. An adequate referral system will need to be in place to ensure that hospital treatment is readily accessible for severely ill people with AIDS. In

order to ensure that hospitalized AIDS patients are not stigmatized, NACO has requested that they are no longer isolated, but treated in general wards. Training programmes for health personnel have also been proposed to encourage less discriminatory practices.

Whether in the community or in a clinical setting, the new emphasis is on the need to protect the rights of those affected by HIV and AIDS and to support rather than marginalize them. To this end, efforts are being made to develop HIV/AIDS counselling activities. To date, counselling has involved little more than a discussion of the medical implications of HIV/AIDS and of methods of preventing HIV transmission. The new strategy introduces the concept of psychosocial support and emphasizes the need for dialogue rather than instruction.

Conclusion

Since the creation of the National AIDS Control Organization in 1992, there have been many positive developments in policy and legislation relating to HIV and AIDS in India. NACO has reacted positively and quickly to new approaches in international AIDS policy, most particularly those advocated by the World Health Organization's Global Programme on AIDS. Thus, the earlier official response, which was characterized by conservatism and discrimination, has been replaced by an approach which emphasizes the rights and dignity of people with HIV, which seeks to communicate with those who are vulnerable to the disease rather than instruct them, and to support rather than punish them. Considerable progress has been made in establishing the structure and mechanisms of a coherent National AIDS prevention and control programme and in directing resources towards interventions to prevent the transmission of HIV. To this end, NACO officials have confronted highly sensitive issues and have demonstrated a willingness to challenge cultural taboos surrounding sexual behaviour in India.

The progressive approach of national-level policy-makers has been countered, however, by conservative forces at the state and local levels. With important exceptions, state governments have shown a reluctance to launch health education campaigns that talk openly about sex and condom use. Bottlenecks have occurred in the distribution of funds for AIDS projects and in the recruitment of personnel. Due to the stigma attached to working with high-risk groups,

especially in the context of AIDS, many government officials are happy to pass the responsibility for HIV prevention activities to the non-governmental sector. Whilst this has paved the way for projects of a more innovative and challenging nature, it has permitted the growth of NGOs which seek little more than funds and prestige. Problems of implementation have also stemmed from conflicts of interest between different State sectors. On the one hand, health departments are expected to take an inclusionary approach to groups such as CSWs and IDUs. On the other, State bodies in charge of public order and law enforcement are expected to arrest them.

Whilst such constraints are of a short-term nature, a more fundamental problem with NACP is that it continues to emphasize medical aspects of AIDS at the expense of social and economic dimensions. As a result, it takes insufficient account of the wider social context that puts targeted individuals at risk in the first place. Individual vulnerability to HIV is generally increased by poverty, lack of education, poor self-esteem, poor health and nutrition (associated with increased need for blood transfusions or injections), low social status and lack of sexual autonomy. These factors cannot be addressed by 'selective' programmes that focus exclusively on HIV/AIDS prevention but demand an integrated and comprehensive approach that concentrates on broader development issues. In the Indian context this means challenging double standards which result in the strict control of women's sexuality, sexual freedom for men, and commercial sex for large numbers of impoverished women; abolishing the social inequalities that sanction the rape and sexual exploitation of lower caste women by upper caste men; and addressing the economic inequalities which deprive large numbers of people of access to adequate health and education facilities, which promote long-term migration and the breakdown of normal family life, and which result in the entry of impoverished men and women into the commercial blood and sex industries. Such goals may be outside the sphere of influence of India's health planners, but if the AIDS epidemic in India is to be effectively challenged, they must be on the policy agenda.

References

- Asthana, S, Oostvogels R (forthcoming) Community participation in HIV prevention: problems and prospects for community-based strategies amongst female sex workers in Madras. *Social Science and Medicine*.

- Arnold D. 1993. Sexually transmitted diseases in nineteenth and twentieth century India. *Genitourinary Medicine* 69(2): 3-8.
- Baweja H, Katiyar A. 1992. The Indian face of AIDS. *India Today* 30 November, 1992: 92-7.
- Bharucha ZS. 1992. Strategies for ensuring safe blood and blood products. *CARC Calling* 5(1): 40-2.
- Chatterjee A. 1991. AIDS in India: emerging from initial chaos. *AIDS Watch* 13: 3-7.
- Dasgupta PR. 1994. NACO's intersectoral linkages: achievements, strategies and hopes. *AIDS in India. Newsletter of the National AIDS Control Organization* 2: 2-5.
- De Souza S. 1990. Prostitution and AIDS. *Social Action* October-December: 405-16.
- Girimaji P. 1990. India: less complacency now. In: Panos Institute. *The 3rd Epidemic: Repercussions of the Fear of AIDS*. London: The Panos Institute; 190-94.
- Girimaji P. 1992. Professional blood donors protest. *World Aids* 5(7): 9-10.
- Government of India, Ministry of Health and Family Welfare. 1991. Draft Strategic Plan for the Prevention and Control of AIDS in India, 1992-1996. New Delhi: Government of India.
- ICMR. 1987. Sero-surveillance for HIV infection in India. *ICMR Bulletin* 17(12).
- ICMR. 1988. HIV infection - ongoing studies and future research plans. *ICMR Bulletin* 18(11).
- ICMR. 1989. HIV infection - ongoing studies and future research plans. *ICMR Bulletin* 19(11).
- ICMR. 1990. HIV infection in women. *ICMR Bulletin* 20(11 and 12).
- ICMR. 1991. HIV infection - current status and future research plans. *ICMR Bulletin* 21(12).
- ICMR. 1992. HIV infection: current dimensions and future implications. *ICMR Bulletin* 22(11 and 12).
- India Today* 30 November, 1992.
- Jayaraman KS. 1992. Injecting drug users in India: 'little Manipurs all over'. *World AIDS* 5(5).
- Muley DS. 1994. AIDS education in schools: some issues. *AIDS in India. Newsletter of the National AIDS Control Organization* 2: 8-10.
- Naik TN, Sarkar S, Singh HL, Bhunia SC, Singh YI, Pal SC. 1991. Intravenous drug users: a new high-risk group for HIV infection in India. *AIDS* 5(1): 117-8.
- Nataraj S. 1990. Women freed from illegal detention. *World AIDS* 3(9): 3.
- National AIDS Control Organization. 1993. *National AIDS Control Programme India. Country Scenario: an update*. National AIDS Control Organization, Ministry of Health and Family Welfare, Government of India. April 1993.
- National AIDS Control Organization. 1994. *AIDS in India. Newsletter of the National AIDS Control Organization* 2.
- National AIDS Control Organization. 1995. Unpublished data. Personal communication, Dr Robert Oostvogels, AIDS and Anthropology Group, Medical Anthropology Unit, University of Amsterdam.
- Personal communication, Dr Jayapul, STD Department, General Hospital, Madras, Tamil Nadu.
- Pioneer*, 22 July, 1993.
- Pioneer*, 12 August, 1994.
- Ramasubban R. 1990. Sexual behaviour and conditions of health care: potential risks of HIV transmission in India. Paper presented at the seminar on Anthropological Studies Relevant to the Sexual Transmission of HIV. IUSSP in collaboration with DANIDA, Sonderborg, Denmark, 19-22 November, 1990.
- Singh IP. 1990. *Indian women: the power trapped*. New Delhi: Galaxy Publications.
- Times of India*, 22 April, 1994.

Acknowledgements

The contribution to this work of S Aggarwal is gratefully acknowledged, as are the very helpful comments of the anonymous referee. This study was supported by a grant from the Nuffield Foundation.

Biography

Sheena Asthana is a Senior Lecturer in Social Policy at the University of Plymouth. She graduated from the University of Oxford in Geography and obtained her PhD from the London School of Hygiene and Tropical Medicine in 1991. Working mainly in India, her research interests include the role of community participation in health development, women's health and AIDS.

Correspondence: Dr Sheena Asthana, Senior Lecturer, Department of Social Policy, Faculty of Human Sciences, University of Plymouth, Drake Circus, Plymouth, PL4 8AA, UK.

